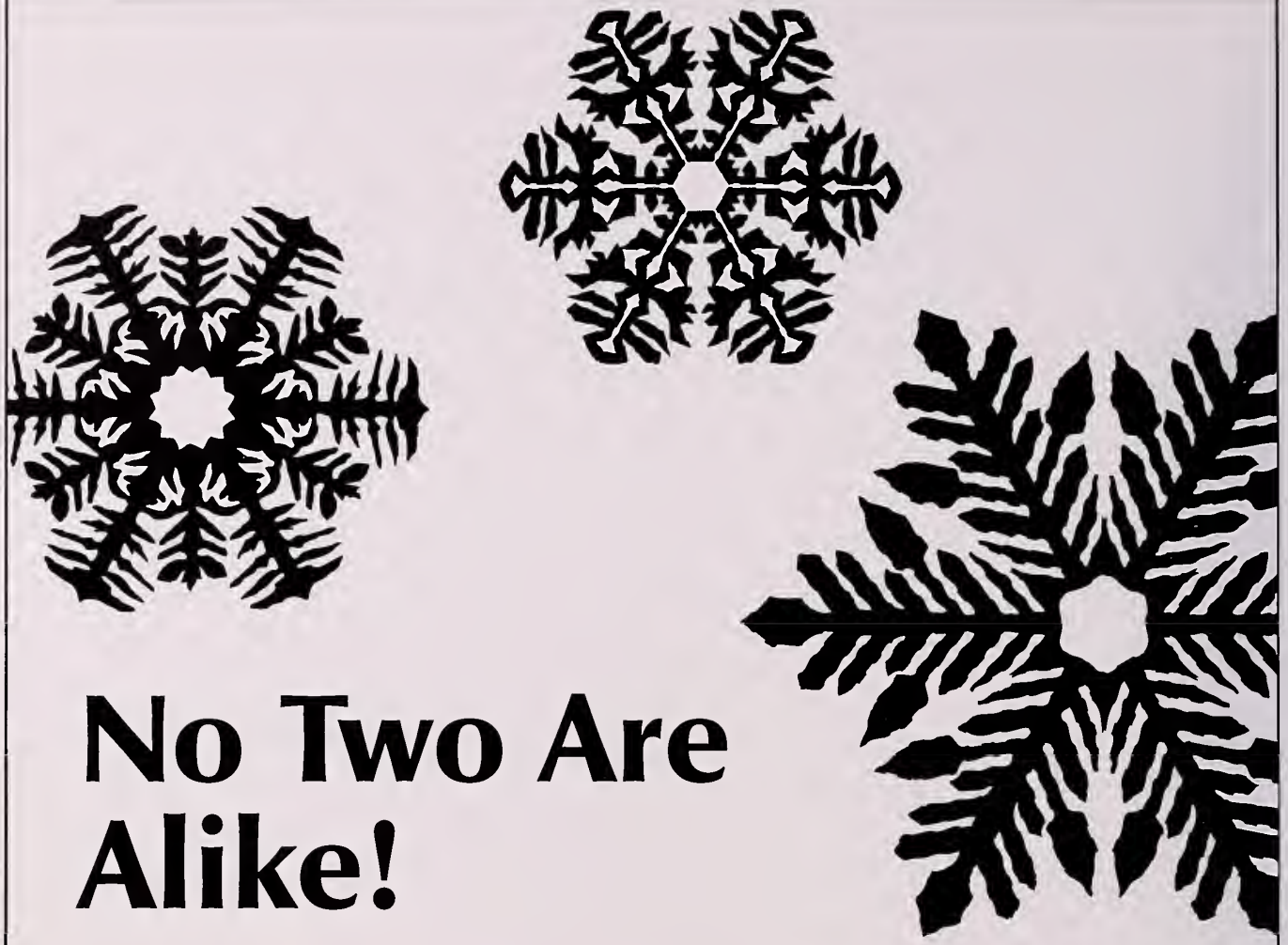
Harvard Medical

ALUMNI BULLETIN WINTER 1998

Voices of Disability



No Two Are Alike!

Just as snowflakes are unique–so are people, but we all share a common bond–that's the need for blood. This winter, please give blood, and give others a chance to improve the quality of their lives.

Call the **American Red Cross at 1-800-GIVE-LIFE (1-800-448-3543)** for the blood drive or donor center nearest you. Our blood donation centers are located in: Dedham, Peabody, Worcester, and Springfield.

American Red Cross
Blood Services - New England Region

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Photo by Stuart Darsch

Inside HMAB

The politics and psychology of word choice are nowhere more peculiar than in the current preference for the term disability over handicap. Etymology and historical associations are all in favor of the latter.

The basic meaning of disability is incapacity, a flat disqualification from the task at hand. As recently as a century ago the main use of the word was legal and referred to the lack of equal opportunity characteristic of such inferior beings as minors, slaves, women, and those without real property. An earlier sense, that one simply lacks the capacity to do a particular task, had pretty well slipped into obsolescence. The term occasionally appeared with reference to illness or developmental problems but was not much differentiated from, or less disparaging, than the equivalent labels of the time.

Handicap, on the other hand, arises from a kind of wager that was popular in the Middle Ages. Two people would offer to exchange something in their possession, say a cloak and a hood; they would thereupon place wagers in a cap that an umpire held. The umpire would then give his opinion of the relative worth of the items. Who got the wagers depended on whether one or both parties agreed to stay with the exchange. The name of this process, handicap, was a kind of synecdoche, referring to the act of handing the wager into the cap. (Thus, contrary to a criticism sometimes leveled against the term handicap, its origin has nothing to do with the beggar's practice of standing cap in hand to ask for alms.) Handicap went on to acquire a somewhat new, but clearly related meaning in sport. It now describes a process by which two people or animals known from past experience to have different capacities are allowed to compete in the same contest.

Both concepts are necessary. It would be an utter failure of compassion to deny that disabilities are indeed disabling in at least some domains of life. But by the same token there are many times when allowing for a handicap, in the gaming sense, brings needed talent to the field. It is in this spirit that we devote an issue of HMAB to "disability."

William Ira Bennett '68

Harvard Medical
ALUMNI BULLETIN

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Letters

Fit to Print

Since reading the excellent obituary of Lamar Soutter '35 in the spring issue of the *Bulletin*, I have recalled many wonderful moments I was privileged to spend with Bemie (or Bimi as I sometimes have seen it written) during my residency years in surgery at the MGH from 1946 to 1951.

In particular, I believe he should receive an additional bit of recognition for his superlative sense of humor and his strong bent for puncturing the balloon of pomposity with his sly but gentle lampooning lancet. In the fall of 1950 Bernie approached me with the idea of preparing a spurious edition of the *MGH News*, and with all due modesty I confess that I jumped at the chance to join him in his Machiavellian purpose. I came to the end of my residency at the end of December, and we plotted our course.

The printing company that produced the *MGH News* was contacted and acquainted with our desire to have them duplicate the format. It required considerable tact and diplomacy to convince the printer that he would not be subject to guilt for the crime, but when assured that we would provide a new engraving for the seal of the MGH, (the figure of an MGH student nurse, holding a bedpan and a lily being substituted for the Indian), and we swore to absolve him of all blame, he capitulated.

Needless to say, Bemie was the major of this cabal, and his contributions to the issue No. 97A for February 1951 were most prominent. We labored in gleeful expectation of a remarkable tour de force, and when the edition was at hand, I surreptitiously inserted them in the postal boxes in the old brick corridor in the wee hours of the night, and crept back to my bed in the Mosely building to await its reception. We were unable to induce the printer to mail additional copies to those who received them outside the hospital and had to be content with only the denizens of the hospital.

Those who remember the contents of No. 97A need to know that Bemie was responsible for "Progress In Anaesthesia," a presumed lecture by Henry K. Beecher, given before the American Congress of Anesthesiologists at, of all places, the Boston Garden. At the venerable MGH, in the shadow of the Ether Dome atop the Bullfinch Building, he wrote "For many years we believed, as did every thinking anesthesiologist, that ether was the agent of choice when used by the proper hands. . . .Today, we can face the world as Morton did in 1846 and announce the discovery of an even more remarkable anaesthesia which will revolutionize surgery of the future. This agent, or combination of agents, has been on trial for some months under the name of Formula X. . . . Curare, the chief and most important of these, has been used wrongly. . . for this drug to be safe and effective it was vital to use it with appropriate amounts of other agents. . . . With it must be blended a small amount of ethylene, a dash of cyclopropane, a sprinkling of avertin, stir in some pentothal, add nitrous oxide to taste, and you have perfect anaesthesia."

One of his best contributions concerned "the machine that cleans the brick corridor." This was a machine to take over the duties of Georges Accropolis and his pail of water and mop, to be designed and built by the Baldwin Locomotive Works. That company, he wrote, "considers it to be its most formidable mechanical achievement, and has a large painting of it in their main office. In action it is magnificent, as it courses down the hallways lit by the strong beam of its searchlight, the walls resounding with the powerful pulsating throb of the electroturbines, its mechanism sucking in the filth from the floor and then spewing it out behind in a broad wave of homogenized dirty water. Its effectiveness is amazing. In a day's time it can cover the corridors, yet its operation requires but three persons: Mr. Putillio to guide it skillfully, the custodian of the cable to tend its high voltage electric cord and of course, at a safe distance behind, Mr. Accropolis, with his mop and his pail to clean up the mess."

The plans for the "new south surgical service" and "elevators lauded at MGH" among many other notes were classic Bemie. Recent publications were a source for needling artifices at the expense of Simmy Simeone, Arthur Allen, Claude Welch, Richard Sweet, Robert Linton, and of course, No. 31 in a series of staff photographs, the new head of the animal farms, Dr. Walter P. Bauser, a scruffy dog.

Even now, some 46 years later, I am occasionally approached by some with long memories to quote from or recall their favorites from that spurious parody, to revive fond memories of that beloved collague and mentor, Lamar Soutter, whose like will not soon be seen again.

J. Roger Newstedt '42

Letters

Successful Recovery

I am an HMS graduate and also a recovering alcoholic, dry some 18 years now, thanks to my friends on earth and above. I noted with laughter William D. Clark's (summer 1997) statement,". . . . brief intervention . . . . Extensive research shows the success of this approach for alcohol. . . ."

If only this were true! When I was in Boston in the 1940s, this was tried as well as "number 88B," which was what MGH called a phenobarbital mixture, and we sang a song about 88B to the tune of "In My Arms." These methods, as well as our voices, failed miserably!

I was sorry not to see in his article a mention of the real successful treatments of AA and NA, but in his grief, perhaps it was an oversight.

Name Witheld Upon Request '48

Harvard Nutrition

The summer 1997 issue of the *Bulletin* had four pieces relative to nutrition. But I was disappointed that none of the pieces mentioned that Harvard has had a very active department of nutrition since 1942. The department was made possible by a large grant over a period of five years from the Rockefeller Foundation. It is in the School of Public Health, but has instructors in the medical and dental schools. Staff members have given lectures and discussion sessions in the Business School, the School of Education and to Harvard undergraduates.

In 1962, at the request of President Pusey and the late Dr. Farnsworth of the Harvard Health Services, the department organized what was called the Nutrition Committee. It was set up to function as a liaison among the various groups in the university that were concerned with aspects of health and health services related to food and nutrition. It is described in the April 1994 issue of *College Health*.

Those of you who might like to know more about Harvard's Department of Nutrition will find my book *Adventures in Nutrition* published in 1991 of interest. Nearly 3,000 research and educational papers are listed by title and reference. The book is readily available in the Countway Medical Library.

When the department started in 1942, there were only three members; it was the smallest department in the School of Public Health, with an annual budget of $26,000. It expanded rapidly until 1962 when it was the largest department in the school, with a staff of 25, a like number of postdoctorate fellows, several graduate students and a budget of $4 million. We also moved into a new building providing 64,000 square feet of space—80 percent of which was provided by private funds and 20 percent from the National Institutes of Health.

Frederick J. Stare, PhD, MD
Distinguished professor emeritus, founder, Harvard's Department of Nutrition

Dean Joseph Martin

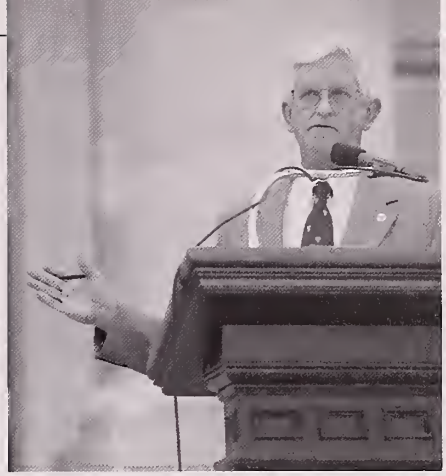


photo by Liza Green

Greetings to the Class of 2001

Dean Joseph B. Martin opened the doors, both literally and figuratively, to the incoming Class of 2001. As part of orientation, the doors of Building A onto the Quadrangle, which are traditionally only opened for Commencement and Alumni Day, were unlocked and will stay unlocked from Monday through Friday, 9 a.m. to 5 p.m.

Martin welcomed the 168 new medical students and 32 dental students to the Harvard medical community: the alumni, faculty, residents and postdocs at the 17 affiliated institutions.

He told them that the front doors of HMS would be open to them as a symbol "of my commitment to go with you through your transition into the medical profession."

He said that the open doors also represent his priorities for HMS: "We in this building will be open and accessible to all our communities; at the same time, we will be looking for ways we can be of assistance—to our students seeking knowledge, our affiliates seeking collaboration, or a neighborhood health clinic seeking another pair of hands."

With the doors open, he said that during his tenure here, "community outreach and service will remain an individual choice but will be a mandate for HMS as an institution." He told students to think carefully about how they interact with all their communities: the HMS community and neighboring communities in Boston, the United States and around the world.

"Carefully consider ways that you can take your membership in the Harvard medical community as an opportunity to become leaders in using the science and the art of medicine to make all our communities better. As a result you will become better members of the medical and dental profession."

The Class of 2001 is composed of 44 percent women and 56 percent men; 48 percent are white, 27 percent Asian, 11.5 percent African-American, 7 percent Latino and Mexican-American. Fourteen are international students.

photo by Liza Green

photo by Graham Ramsay

Orah Platt

New Master of the Castle

Echoing the modesty of William Castle, who said he didn't know why a society would be named after him, Orah Platt '73 was surprised by the opportunity to become master of the Castle Society. "It was a great honor, but it did come as a bolt from the blue."

Platt, HMS professor of pediatrics, takes the reins from Marian Neutra, who decided to step down after five years as master. Platt is particularly interested in helping students make the transition from classroom learning to work on the wards. "I'm interested in the interface between the first two years of basic work and the clinical work. I want to make that a smooth transition, to make sure we're really meeting the needs of our students and what's being demanded of them."

For the last few years, Platt has led the basic science course on hematology that second-year students take. Aside from lectures, other teaching methods are used, such as tutorials, mini-case studies and World Wide Web-based tools. "We're interested in seeing what the outcomes of student performance are, depending on how the learning took place; what's most effective for certain types of material and certain students; and which methods have the best outcomes. That really hasn't been studied carefully."

In an example of things coming full circle, Platt, who studied under Castle, also plans to involve Castle Society students in her research on the molecular basis of sickle cell disease. "This is research that is in large part inspired by Dr. Castle himself."

Platt's own experience as a student at HMS will inform her work as master. "Ultimately, I'd just like to concentrate on the students and on doing what I can to be sure their experience is as happy and satisfying as I had when I was in medical school."

Dean Affirms Diversity

Pins proclaiming "celebrate diversity" were passed out as people swelled the Carl W. Walter Amphitheater to capacity on October 15. They had come to hear Dean Joseph B. Martin discuss diversity in the Harvard medical community.

William Silen, the HMS faculty dean for faculty development and diversity, introduced Martin by saying that the announcement of a new dean had created speculation about what the new dean's views would be on diversity issues, particularly since he was coming from a state that had passed a proposition to abolish affirmative action. Silen was quickly assured that in Martin we would have a dean who has and will continue to be dedicated to diversity efforts. In fact, students at UCSF, where he was chancellor, had bestowed on him their Martin Luther King Award.

Martin started his talk by affirming that this issue would be one of his top priorities here as it was at UCSF, but acknowledged that California's Proposition 209 and similar propositions in other states were "part of a nationwide assault on affirmative action admissions policies." In the case of California, the proposition was triggered by white parents whose son was denied admission to the University of California/San Diego's medical school, he said. The protest eventuated in a proposition passed in June 1996 with a 59 percent majority, and which has survived legal challenges. "It has had devastating effect," says Martin. One example: UC/Davis admitted no black students this fall.

"Affirmative action is, as it has been, a tool," he says. "The goal to enrich diversity is to enrich the experience of all."

Whereas HMS has done well in enrolling underrepresented minorities—about 20 percent of the classes—only 2 percent of the faculty are from underrepresented minorities, a statistic that hasn't changed in three years. Part of the problem, he says, is that only a small number of minorities choose academia, and "too many leave Boston to train."

"I promise to use my bully pulpit to encourage clinical directors here to consider strongly minority candidates to their residency programs."

He also pointed out that the number of minorities applying to medical schools is dropping off. HMS has some very successful programs designed to encourage careers in medicine and science in high schools and colleges. "But I believe that we can expand our efforts by creating more synergy through coordination and collaboration as well as developing new initiatives to promote the long-term strength of HMS and the medical profession as a whole," says Martin. He pledged his full support to Silen in convening the leaders of all such programs as well as the chairs of all departments to discuss their recruitment progress.

"This is a bold new diversity initiative on which we'll embark."

photo by Graham Ramsay

Dennis Kasper, the HMS William Ellery Channing Professor of Medicine at BWH, is now also the executive dean for academic programs.

Collaboration Among the Hospitals

To enhance joint academic programs and increase collaboration, HMS Dean Joseph Martin has begun a series of discussions with representatives of CareGroup and Partners Health System.

"At a time of Medicare cutbacks and increasing pressure to reduce costs from all payers," said Martin, "we agreed to review the benefits for medical education, biomedical research and patient care that might flow from increased cooperation among the faculty of the two systems."

Although still in the preliminary stage, a few initiatives have been outlined. One concerns the National Cancer Institute's Comprehensive Cancer Center program, a designation held by the Dana-Farber Cancer Institute. With the application for the designation renewal due in 1999, there is the potential to change the designation to include all oncologists in the Harvard medical community, under the title, Dana-Farber/Harvard Comprehensive Cancer Center. Martin and the president of DFCI, David Nathan '55, have asked David Livingstone to chair a planning committee devoted to this effort.

HMS Dean for Academic Programs Dennis Kasper is leading a second initiative to create a clinical trials program for diseases other than cancer. He is currently recruiting a clinical affairs dean to oversee the establishment of a Harvard Clinical Trials Center.

Other discussion has focused on consolidating certain clinical laboratories among the hospitals, which would reduce the cost of patient care and make clinical trials more efficient. In addition, there is talk about consolidating some specialty residency training programs in an effort to expose interns and residents to a broad section of patients.

Whereas a variety of such joint-venture projects are being considered, a merger between Partners and CareGroup is not being discussed. Each system remains committed to developing its own integrated health care delivery system.

Post.Harvard

In December the Harvard Alumni Association (HAA) unveiled an e-mail forwarding service that enables Harvard alumni to stay in touch with one another electronically. The service, "Post.Harvard," is free and available to all who have graduated from Harvard or its graduate schools.

"Post.Harvard provides alumni with permanent e-mail addresses at which they can always be reached," explains Terry Shaller, senior associate director of HAA. "If their e-mail addresses change because of job transitions or if they've switched service providers, they need only notify Harvard of the change." Shaller emphasized that Post.Harvard is an e-mail forwarding service, not an e-mail account.

Subscribers can register for the service through Harvard's Alumni Affairs and Development Web site, Harvard Gateways (www.haa.harvard.edu). After providing personal information that will be authenticated against university records, alumni will be asked to choose their own Harvard e-mail forwarding name and provide the address of their preferred e-mail account. An online e-mail directory will allow friends and classmates to search for a Post.Harvard subscriber.

According to Shaller, Post.Harvard is the beginning of an exciting variety of services that will be offered to Harvard alumni through Gateways.

"Real-time discussions, online chats with faculty and fellow alumni, and live broadcasts of Harvard sporting events are just a few of the interactive services we plan to offer Harvard alumni and alumnae," says Shaller. "We think Post.Harvard will make alumni feel more comfortable about interacting with Harvard electronically."

Pulse

Many months in development, Post.Harvard has been designed to take advantage of the most current Web technologies. Special attention was given to the importance of restricting this service to Harvard University alumni. Post.Harvard, as with all other alumni information, will be subject to existing university policy prohibiting the use of distribution of e-mail information for any purpose not directly related to university business.

At the HAA Board of Directors meeting in October, Post.Harvard received overwhelming support from alumni.

photo by Liza Green

Caring is Primary

This year, HMS celebrated National Primary Care Day with events lasting not one but two weeks. The celebration included a variety of seminars on everything from primary care in gay, lesbian and bisexual communities to domestic violence to community outreach. These activities were capped by an address by Dean Joseph B. Martin on the art and science of communication in medicine, which also inaugurated the year's Cabot Primary Care Series.

Noting that almost three-quarters of the first-year class has signed up for the Primary Care/Family Medicine Mentorship Program, Martin said, "The tool of communication is absolutely vital to all physicians, but to those interested in primary care, it had better be the most well crafted tool in their kit."

Martin stressed that the art of communication encompasses not only knowing how to communicate information to patients but also knowing when to communicate uncertainty. He also discussed the importance of overcoming racial, cultural and economic gaps between doctors and their patients. "Treating your patients

photo by Liza Green

Ethnic foods, arts and crafts, music and dance were the ingredients for the first HMS Annual Global Harmony Festival on October 9, 1997. A tent full of different cuisines created a party-like atmosphere on the Quad, as cultures and traditions from around the globe were represented. Judging from the turnout, the organizers hopes of it becoming an annual event look promising.

Thomas Inui, director of the Division of Primary Care, was one of the many who enjoyed this year's Cabot Primary Care Series.

President's Report

by Robert S. Lawrence

means treating your patients' fears and doubts, no matter how ill-founded or strange you think they are, as well as their medical condition." He emphasized the value of being good communicators as well as scientists.

Martin closed by outlining five points that the "compleat" physician should keep in mind: acknowledging that patients know science will probably never provide a full understanding of human emotions, such as happiness and hopelessness; that many patients will seek alternative therapies in addition to the conventional; that healing is a complex process, assisted by a physician's scientific knowledge, but also propelled by less well understood factors, such as the patient's will to live and fortitude against all odds; that spirituality, in one form or another, is present in the majority of people; and that a substantial proportion of patients are medically sophisticated and will often come in with questions that surprise the physician.

The fall meeting of the Harvard Medical Alumni Association was largely devoted to medical education and student life at HMS. A student representative from each of the five faculty-student societies joined the council to share information about and impressions of the New Pathway during informal conversation over dinner. After dinner they recounted stories of their personal pathways to HMS, which ranged from serving as a legislative aid on Capitol Hill and a member of the domestic policy council in the White House to eight years as a lineman in the NFL—earning a Super Bowl ring while playing for the Washington Redskins.

The council then retired to their homes or hotel rooms to prepare for tutorial the next morning. Singly or in pairs, we joined second-year tutorial groups and observed the students working their way through the case of a young woman with invasive carcinoma of the cervix. For most members of the council it was our first direct exposure to the problem-based, case-method tutorial now forming the core of medical education during the first two years at HMS. The information sharing and mutual instruction among the students were stunning; the restraint and relative silence of the tutors were remarkable; and the subject matter reviewed was breathtaking in its range—from the molecular biology of oncogenic viruses to the purposes of staging clinical cancers to lost opportunities for prevention.

Post tutorial the council debriefed with Orah Platt '73, master of the Castle Society, and Daniel Federman '53, trading his director of alumni relations hat for that of dean for medical education. The conversation wove around the obvious engagement of the students as active learners, the difficulty of adopting the HMS program in other medical schools lacking the size and scope of the Harvard faculty, the challenge of recruiting adequate numbers of tutors, even with the size of the Harvard faculty, and the continuing quest for the optimal balance between the biomedical content of the curriculum and the social and behavioral aspects so critical to optimal patient care.

The discussion included the application of new technologies for medical education, affording Orah Platt an opportunity to describe the website for the hematology portion of the pathophysiology block. She and her faculty place lecture notes, laboratory instructions and other course material on the Web, as well as responses to the most frequently asked questions from the students. In addition to the obvious close personal interactions taking place among faculty and students in the tutorial setting, the application of "asynchronous" instruction in the electronic medium of the Internet opens new lines of communication for the students regardless of the hour or place of study.

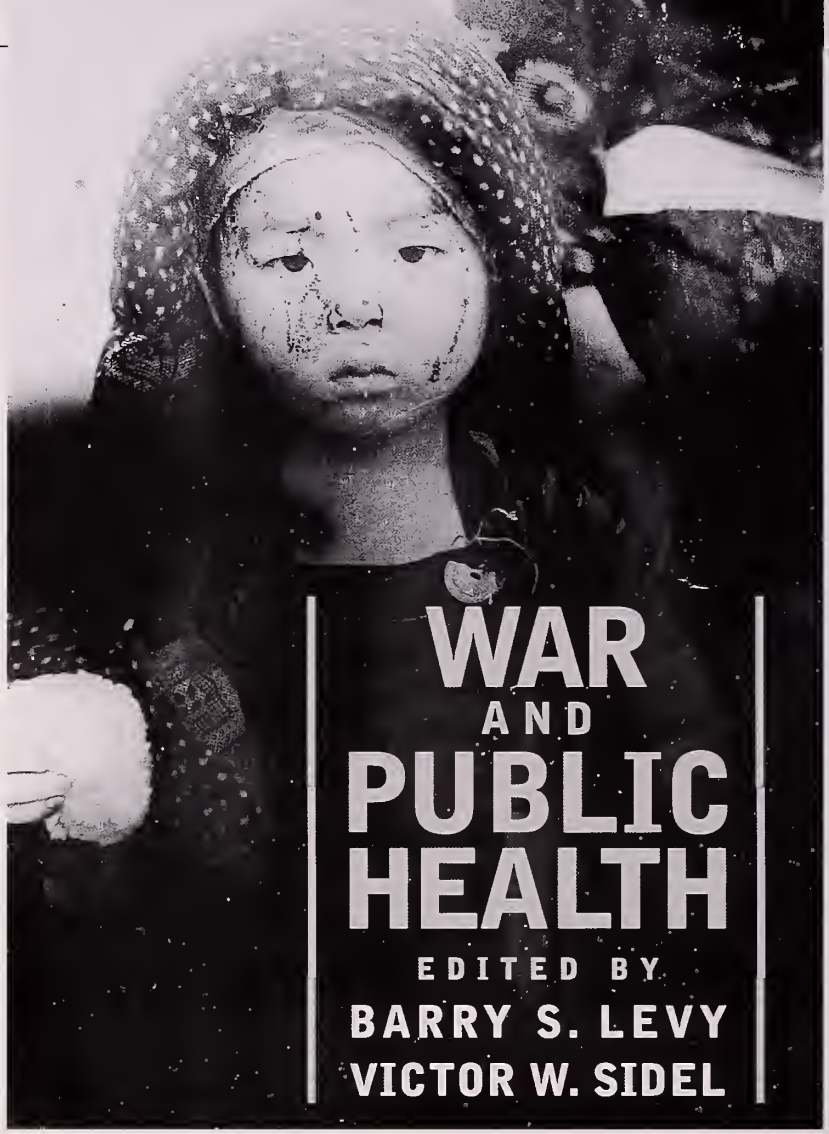
Nancy Oriol '79, the new associate dean for student affairs, and Audrey Bernfield, director of enrichment programs, described the community and outreach programs now available in growing numbers to the students. Many groups are student-initiated and student-directed; others are community-based organizations that welcome student volunteers; and still others offer stipends for summer work and term-long employment. A few of the community projects have fostered research opportunities as well. The council regarded all of these developments as encouraging signs of energy and commitment among the students.

Robert S. Lawrence '64 is an internist, and professor and associate dean for professional education, Johns Hopkins School of Hygiene and Public Health.

Book Mark

WAR AND PUBLIC HEALTH
edited by Barry S. Levy and
Victor W. Sidel
Oxford University Press,
New York, 1997

by Jennifer Leaning



In the mid 1990s, a more intense look than in the past is being directed at the relationship between war and public health. Of the many factors that are undoubtedly at work, certainly three should be noted: the anniversary phenomenon triggered by the passage of 50 years since the end of World War II; the escalation in number and visibility of bloody regional wars around the world; and the increasing participation of the civilian and nongovernmental sector in providing a medical response to these conflicts.

In 1994 an excellent analysis of the interaction among drought, famine and conflict was published: *War and Hunger*, edited by Joanna Macrae and Anthony Zwi. In 1996 Pierre Perrin, medical director of the International Committee of the Red Cross, authored a deeply practical and comprehensive text, *War and Public Health*. And now, in 1997, Barry Levy and Victor Sidel '57, current and recent past presidents of the American Public Health Association, have edited a very different book, albeit with the same title, *War and Public Health*. At least two more books on various aspects of war and public health are due to be published in 1998 and 1999.

Levy and Sidel's text is a landmark book, one that I hope will find itself persisting through many editions well into the next century. This is not to say that it is a perfect book: it omits a number of issues, touches too briefly on some topics and, from my perspective, spends too many precious pages on others. However, it is a landmark because it is intellectually courageous, academically adventurous, and unashamedly both scholarly and idealistic.

The intellectual courage arises from placing the topic of war squarely in the mainstream of the field of public health. For centuries there has been a fine tradition of military physicians and historians writing about issues of health, medical care and diseases of troops and populations during war. This body of literature has always been from the perspective of the fighting army, and has always considered itself, and been classified by others, as history and analysis belonging to topics that begin with the constraining adjective "military."

The development of the field of public health has been a civilian enterprise, much more recent than our understanding of military medicine, and for the most part has studiously avoided the elephant in the room: that for many times and many populations the greatest scourge to public health has been the events wrought by war. Several chapters in this book make that point indelibly, including those dealing with the human consequences of war, the impact of war upon human rights, and three chapters on the effects of war on women, children and displaced persons.

This book is academically adventurous in that it draws heavily and wisely from a body of literature and expertise developed over the last 30 years by well-trained physicians and scientists active in the worldwide movement to limit and eliminate weapons of mass destruction. As inter-

preters of the relatively arcane scientific archives and as independent investigators, these people are now positioned to help us understand the short- and longer-term effects of the development and uses of nuclear, biological and chemical weapons.

It is also these people, and the organizations they have helped found or are affiliated with, who have influenced the civilian, nonofficial side of exploring and promoting a wide range of arms control and disarmament measures. A number of chapters in this book thus look at war in terms of the weapons that have been used or might conceivably be used: nuclear, chemical and biological. It is appropriate that the chapter on land mines is included in the section on weapons systems that slowly or immediately spell mass destruction.

The scholarship and idealism are evident in the introductory chapters exhorting us to see the world through the public health paradigm, in the many chapters in the two sections on the roles of public health professionals and organizations, and inherent in the question of whether war and its public health consequences can be prevented. These chapters are alive with facts, quotes and anecdotes, which move from descriptions of the Red Cross movement to arguments against physician participation in war, and describe interventions ranging from humanitarian aid to conflict resolution to peace education.

War and Public Health is uneven in depth of analysis, sweep of expertise and clarity of focus. To some extent, this unevenness reflects the early developmental stage of some of the topics; to some extent, a lapse in taking a consistently historical perspective; and to some extent, simple variation among authors in aggressive investigation of sources. Particularly excellent chapters are those on population casualties, biological weapons, the effects of nuclear weapons development, production, and testing, and on landmines (although it is too brief and could have included far more historical discussion and analysis of abrogated land use).

Also too brief is the informative and ambitious chapter on the effects of military activities on civilian populations; in some ways, this chapter is a book in itself. In the space allotted, it can address in substantive detail only the U.S. and international arms trade, while mentioning topics that need to be expanded in later editions, such as the effects of militarism on minority populations. The chapters on human rights, displaced persons, preventing nuclear war, physician ethics in war, and the United Nations all reflect careful thought, deft command of sources and considerable expertise.

An important section of the book contains three case studies of wars and their public health effects: Vietnam, Central America and the Gulf War. In many ways these three chapters are the most intellectually satisfying of the book. The chapter on Vietnam manages to bring together in one place a great range of information and analysis, presenting a composite picture of the cumulative horrors of that war and its effects on all warring parties. The other two case studies are also excellent, although as in the study of all war, the sources will become richer and more available as the years pass, memoirs are written, and generations of historians try to make sense of events.

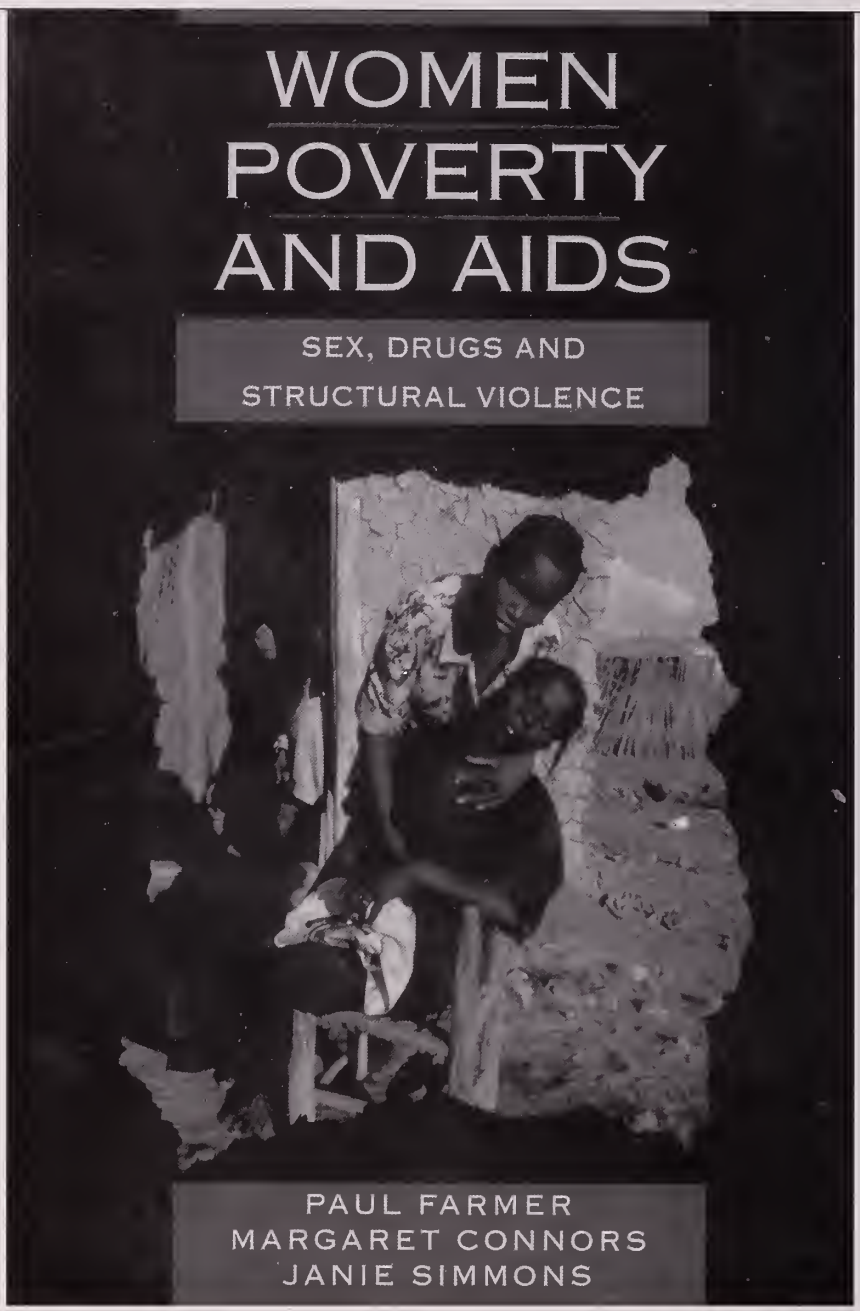
War and Public Health advances an editorial perspective that is predominantly that of U.S. civilians who see little use in war and much harm flowing from it, particularly wars that might be waged with weapons of mass and indiscriminate destructiveness. There is another perspective, not entirely at odds with that, that might arguably be infused: the ways in which the activity of war has improved our understanding of trauma medicine and disease control, defined and codified major branches of human rights law and medical ethics, sustained and trained major segments of all levels of our society, and in some circumstances, although probably not in the three case studies selected for the book, helped secure the world we now all work and live within.

In future editions it might be helpful to include some experts in military medicine and international humanitarian law as contributors, and to contextualize the policy discussions relating to prevention in a framework that distinguishes among different kinds of wars.

Within that framework, the notion of mitigation (reducing the impact and consequences) as opposed to a sole focus on prevention, might be fruitful to explore. Not all wars can be or, I would argue, ought to be prevented. The public health consequences of war, however, now that this book and the others that will follow are helping us see them, might well be within the reach of imaginative and disciplined efforts aimed at protection of vulnerable populations and fragile ecosystems, abolition of entire classes of deadly weapons systems, and strengthening of international and regional interventions in advance of and short of war.

Jennifer Leaning, MD, SMH is HMS assistant professor of medicine, senior research fellow, Harvard Center for Population and Development Studies, and instructor in health and social behavior, Harvard School of Public Health.

Book Mark



WOMEN, POVERTY AND AIDS
eds. Paul Farmer, Margaret Connors, Janie Simmons
Common Courage Press, Monroe, Maine, 1996

by Cindy Telingator

"The World Health Organization predicts that during the 365 days of the year 2000, between 6 million and 8 million women will become infected with HIV." This is one of the many alarming statistics cited in the book *Women, Poverty and AIDS*.

AIDS has been a politicized disease since it was first reported. It continues to infect millions, in part because of the ongoing discrimination that occurs not only in the United States, but globally. Social, political and economic forces worldwide that impede access to prevention and health care are explored critically throughout the book.

Women, and women in poverty in particular, are one of the fastest growing populations who are being infected with this virus. Women continue to die, unable for a multitude of reasons to organize on a community level to obtain services and health care which could prolong lives, if not prevent future exposure to HIV. Paul Farmer '90 and his coeditors attempt to address the discrimination that befalls women, and although no solutions are offered, the authors pose many questions using a substantive combination of facts and life stories.

Women, Poverty and AIDS is divided into three sections. "Rethinking AIDS: Locating Poor Women" provides an overview of the impact of this epidemic on women. The authors posit that poverty and gender inequality are "co-factors" that increase women's risk of contracting HIV. Anatomical differences alone place women at an increased risk relative to men in a heterosexual encounter, but impoverished women are also in a position, for financial reasons, to trade sex or endure nonconsensual sex, and other acts of violence to provide food and shelter for their children and families. This is shown vividly through several life stories of women around the world. Blaming the victim has been a social force plaguing those individuals who have acquired HIV, but from early in the epidemic women have also been chastised for being "vectors" of disease to their children.

This chapter illuminates the multitude of oppressive forces that maintain women, and especially in this country, minority women and their children, at increased risk of contracting HIV. This portion of the book attempts to address these issues and trace the diagnostic and treatment failures of the medical system and the Centers for Disease Control and Prevention. At the end of this chapter the reader is left with a daunting question: how many women will need to die, and how many children will need to be orphaned, before more economical,

medical and community resources are devoted to this population?

The second part of the book, "Rereading AIDS: Examining Claims Of Causality," critiques current research and literature on the topic of women and AIDS in social science, public health and medicine. This portion of the book is informative, but also at times redundant and over-inclusive. The authors present a plethora of literary examples and research to support their premise that the academic and scientific communities have failed to adequately address the dynamic interplay of social forces in the perpetuation of this epidemic. This section is supported by an impressively organized glossary of clinical terms, endnotes and a comprehensive bibliography.

In the final section, "Reconceptualizing Care: Pragmatic Solidarity," the editors have compiled a global cross-section of programs for women with HIV. These community-based organizations offer hope and attempt to compensate for some of the resource failures that are outlined throughout the rest of the book. Although it is helpful to have a directory of programs, the reader may be disappointed that the authors do not offer a critical analysis of the programs they review, as they had with the academic writings and medical trials in previous sections. The absence of this critical overview is notable for those of us in the field searching for resources and innovative programming to help us address the biopsychosocial needs of our patients and their families.

Overall, this is a well written and thought-provoking book which draws much needed attention to the plight of women across the world who are directly and indirectly affected by the threat of HIV. To speak the unspoken is a brave endeavor; to elucidate the social/political/humanitarian injustices that have perpetuated inadequate services for women in this country and globally with HIV is honorable. The authors achieve the goal of addressing the very complicated relationship among gender discrimination, structural violence and poverty as they interface with oppression, global politics and AIDS. But this task is overwhelming and does not lend itself to simple solutions.

Cindy Telingator, MD is HMS instructor of psychiatry and director of Child and Family Services at the HIV Zinberg Clinic at Cambridge Hospital in Cambridge, Massachusetts.

On the Quad

Dean Presents Priorities

At the first meeting of the Faculty Council for 1997/98, Dean Joseph B. Martin outlined his vision for HMS by describing his seven priorities.

The dean's first priority is to maintain and strengthen the basic science departments. He is committed to fostering collaboration, joint recruitments and shared resources. In addition, he is committed to strengthening the graduate education programs, particularly the MD/PhD program. Martin expressed his passion for science and said he places great importance on the quality of scientific work.

His second priority is to improve the relationships between HMS and its affiliated hospitals and other institutions. One of the first steps he has taken to accomplish this has been to establish a physical presence at the major affiliates by setting up space where he will hold office hours. Martin described these satellite offices as HMS embassies that will serve as a direct resource for faculty and students. The first satellite office was opened at MGH in October. Offices at Brigham and Women's, Beth Israel Deaconess, and Children's will be opened later this month.

As his third priority, Martin expressed his belief in the importance of diversity because a more diverse and culturally representative medical community practices higher quality medicine. Martin is proud of minority representation in the HMS student body, but he would like to see an increase in the number of underrepresented minority students in the HMS residency and faculty pipeline.

In addition, Martin expressed concern about the advancement of women. Although progress has been made, as evidenced by a new student population of 50 percent women, Martin indicated that there are still areas, such as the promotion of women faculty members and staff, where more work needs to be done.

He reported that he has charged William Silen, faculty dean for faculty development and diversity, with the task of coordinating all diversity programs throughout the Harvard medical community.

Citing medical education as his fourth priority, Martin said he is impressed with the progress of the New Pathway, but he is also committed to its ongoing improvement.

At the postgraduate level, he stressed the need for HMS to pay more attention to the quality of its postgraduate programs and the well-being of their trainees, especially in areas such as stipend levels, health care and immigration issues.

His fifth priority is the enhancement of information technology at HMS, particularly in the areas of educational, research and administrative computing. One example Martin cited was the progress that the Program in Medical Education has made in enhancing student learning opportunities by establishing new medical education instruments such as the virtual patient system. He plans on promoting the use of information technology in improving the exchange of information in the basic sciences. He noted that he still does not have the capability to easily send an e-mail message to many of his colleagues at the affiliates because there is no comprehensive directory as there was at UCSF.

Martin then discussed community as his sixth priority. He said that public service is an integral part of a complete medical education and stressed its value within the Harvard medical community, the city, the nation, and the world at large. He applauded the efforts of students who undertake public service projects in the community and noted that Harvard Medical International is working to build relationships within the local and international communities.

Martin concluded that for all of our efforts to succeed, resources are essential. Hence, his seventh priority is fundraising. In particular, he plans to encourage scientific researchers, including graduate students and junior faculty, to speak with potential donors interested in medical research.

Following Martin's presentation, the council approved a request for a proposed newly independent physicians' group that will contract with Harvard Pilgrim Health Care to provide care to its members.

Fourteen of Harvard Pilgrim Health Care's health centers in the greater Boston area are being reconstituted as a multisite, multispecialty group practice and are requesting the continued use of the Harvard name for three years beginning on January 1, 1998. The not-for-profit entity will be governed by a board composed of clinician-elected, community, and Harvard Pilgrim-appointed trustees.

Scott Morley

Virtually Patients

Third-year HMS student Anne has osteoporosis on her mind. Why are some women at risk? How do you make the diagnosis? Anne has just come from the wards where she was introduced to a patient with this diagnosis. As Anne studies her notes, she wishes she could have spoken with the patient before her diagnosis, taken her history and gathered more information. Anne can't turn back time, so instead she heads to the Center for Clinical Education at the HMS Beth Israel Deaconess Mount Auburn Institute for Education and Research. It is here that she loads a CD-ROM of the Virtual Patient Project, a computer-based multimedia teaching tool, onto her computer.

On her computer screen, Anne meets Mrs. Brown, a "real life" 55-year-old post-menopausal woman. Mrs. Brown describes her history and as Anne listens, she watches a full-motion video of a live interview with Mrs. Brown, with audio and slide images. Anne asks Mrs. Brown several questions using either the audio or text prompts, and after hearing her answers, wants to see Mrs. Brown's hip X-rays. Anne accesses these X-rays by clicking on a link to diagnostic tests and then reviews two other patients' X-rays for comparison. After hearing what medications Mrs. Brown uses, Anne decides she should see an orthopedist. At the end of Anne's first session with Mrs. Brown, the appointment with the orthopedist is scheduled for one week later, and a review of Anne's visit with the patient is given.

The Virtual Patient Project is one of several HMS Beth Israel Deaconess Mount Auburn Institute for Education and Research projects that show how multi-media teaching tools can further a medical student's education. By July 1 students like "Anne," who are doing clerkships at Beth Israel Deaconess Medical Center (BIDMC), along with house staff, will be able to learn from patients like "Mrs. Brown."

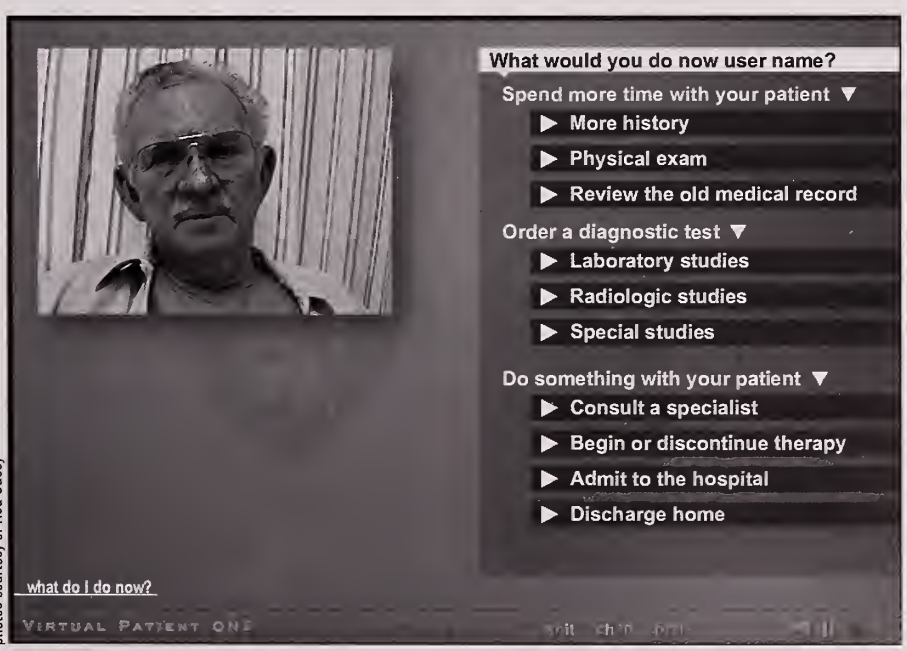
This type of program was one of the goals outlined by the institute's executive director, Michael Rosenblatt '73, the Robert H. Ebert Professor of Molecular Medicine, when the institute was first formed. It is a prime example of the institute's mission to create collaborations between medical education at HMS and BIDMC clinical departments. In the computer common room, state-of-the-art equipment is available to students and house staff 24 hours a day, 7 days a week.

The seeds of this project were sown during the first convening of the institute's council on education in July 1996. Led by Mitchell Fink, chair of surgery at BIDMC, the council is an interdisciplinary committee composed of institute staff, doctors from each of the clinical departments at BIDMC, and representatives from the program in medical education at HMS.

Before council members began discussing the possibility of creating a virtual patient series, James McGee was in Florida videotaping a patient with jaundice whom he had seen in his gastroenterology practice. McGee was hoping to use the videotape for some type of computer-based teaching in the future.

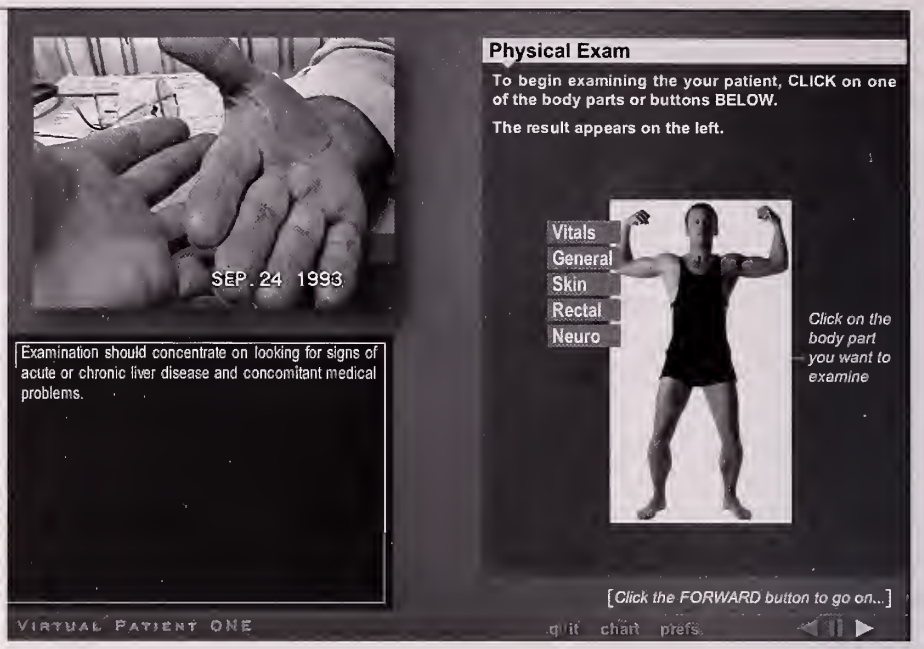
About a year later in July 1997 the institute was awarded a 1.6 million grant from the Josiah Macy, Jr. Foundation to develop 15 virtual patient cases. A grant from Merck and Co., Inc. will fund the development of the virtual patient with osteoporosis. McGee, who had come to BIDMC as a fellow in gastroenterology, is now the institute's clinical educator for multimedia development, and his "jaundiced patient" is the prototype for the virtual patient series.

Although the term "virtual patient" sounds like an oxymoron, the program actually offers medical students the opportunity to fully interact with a patient. For example, as Anne continues with the care and treatment of Mrs. Brown, she will be faced with problems. Mrs. Brown might experience side effects with medications or want a second opinion. It is up to Anne to respond to anything that



photos courtesy of Ned Casey

On the Quad



arises, but she will have help along the way if she needs it. There is a multimedia course that accompanies each of the cases and links to online searches and other resources. Anne will also have access to information on the pathophysiology underlying this condition, which helps integrate the basic science knowledge she's gained in her first two years at HMS.

In addition, Mrs. Brown's attending physician is "programmed" to answer various questions about her care and gives feedback to Anne throughout the case. Anne can either go through this case in one sitting or opt to do it in "real time," with a week or two in between "virtual appointments."

"This is a teaching opportunity that's hard to come by in medical education," says Jane Neill, the institute's program director for academic affairs. "When students see a patient, the patient often already has been given a differential diagnosis. With a virtual patient, a differential diagnosis can be developed by a student from the beginning of a clinical presentation."

Neill points out that students do not see care of the "whole patient" because clerkships are department-based. The Virtual Patient will allow the perspectives of all members of a caregiving team, such as a radiologist, orthopedist or primary care doctor. Similarly, because there has been a move from inpatient to outpatient care, students don't see a full spectrum of illness on the wards. "The Virtual Patient is meant to not only fill in the gaps, but also broaden a student's experience," explains Neill.

This type of computer technology also offers many options for learning about a specific illness or condition. "A student can look at this 55-year-old postmenopausal woman and then jump back in time and look at her when she was age 6, 25, 40," observes Neill. "Also, preventive, pediatric or hormonal issues can be built in."

Although computer-based teaching in the field of medicine is still considered somewhat novel, the center's multi-media specialist, Ned Casey, says that it isn't so new in other environments. "Computer-based teaching has been used by the military, corporations and educational institutions for the last 10 to 15 years. It's been found that people retain 50 to 60 percent of what they learned through this method, which is about double from what is retained through lecture."

The potential downside to this learning tool has already been addressed. A common problem with computer-based teaching, says Neill, is that it's often not integrated into the present curriculum. Thus, HMS faculty developing the cases keep the HMS core clinical curriculum in mind. The cases chosen are considered "must see diagnoses" for third- and fourth-year students. In addition, there is a multidisciplinary Virtual Patient Advisory Committee, chaired by Steven Weinberger '73, the institute's director of medical education, and medical students and course directors will be consulted during development of the series to ensure relevance and integration within the curriculum.

The first four virtual patient cases are slated to be completed in June and will be piloted in core clerkships in July. Along with the jaundiced patient, there will be a virtual patient with HIV, a normal newborn, and a CD-ROM focusing on common dermatological conditions. In January 1998 the next four cases—abdominal pain, altered mental status, chest pain and a woman at midlife—will begin to be developed by faculty at BIDMC or Mt. Auburn Hospital. Faculty who wish to develop a case must submit a proposal to the institute, with each case taking about one year to develop.

In no way is the Virtual Patient intended to take the place of either classroom teaching or seeing "real" patients on the wards. "Why not have live experience be complemented by computer experience?" asks Neill. Indeed, she hopes that as a matter of course, when students are in between cases in the OR, they'll walk down the hall, pop in a CD-ROM of a comparable case they just saw, and continue their learning.

Janet Walzer

Benchmarks

by Gabrielle Strobel

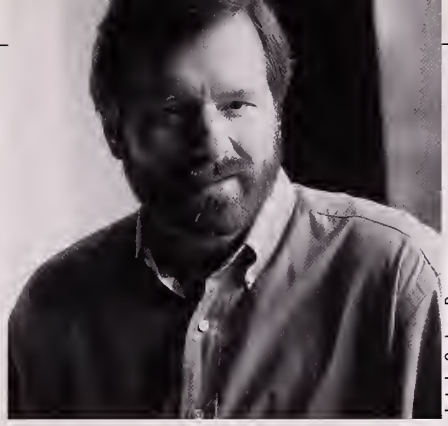


photo by Graham Ramsay

Lewis Cantley

The Cell's Inner Skeleton

Without an inner skeleton, our cells would be limp little bags that drift aimlessly, like jellyfish through the sea. Of course, nothing about cells is aimless or limp: cells assemble proteins inside them into a structured skeleton and then harness this exquisite order to become surprisingly strong and agile.

Indeed, this order allows cells to be, at various times: rigid or soft, still or mobile. The cytoskeleton reconstructs itself whenever the cell needs to change its shape and behavior in response to environmental demands. For example, a cell that sits stiffly one moment can within minutes "morph" into a squishy, crawling bleb that squeezes through tiny openings.

For years, the cytoskeleton has captivated scientists but also eluded them. It has revealed just enough secrets to hint that it somehow figures into most fundamental biological processes, including movement and growth. It also shapes the functional identity of cell types, be it a platelet's power to stop bleeding, a yeast cell's ability to bud off daughter cells, or an embryonic neuron's capacity to explore the territory it is entering. Yet the cytoskeleton is so complicated that it has defied attempts at a complete understanding of it.

Recently, however, scientists have begun closing in on their moving target. They have assembled a mosaic of bits and pieces of information that may soon fall into one big picture. Meanwhile, this field has become "the major new direction of research in the Department of Cell Biology," says Lewis Cantley, a professor in that department who works at the Harvard Institutes of Medicine through Beth Israel Deaconess. "Our recent faculty appointments have focused on people with an interest in that area." Many researchers across the university are working in this emerging field. While the basic research intensifies, it is already beginning to pay practical dividends (see sidebar).

Movers and Shakers

Part of the research has focused on the proteins that perform the dynamic changes of the cytoskeleton. The most abundant protein of the cytoskeleton is actin, which constitutes up to 20 percent of a cell's protein content. At any given moment, about half of a cell's actin occurs as monomers; the other half is strung into twisted, polymeric filaments. Some of these strands cross-link to form a continuous mesh running just under the cell's outer membrane, whereas others line up to form bundles that span the middle of the cell.

Of the roughly 100 different proteins thought to bind to actin in living cells, a handful serve to disassemble filaments in one area of the cell and rebuild them elsewhere, says Paul Janmey, associate professor of medicine at Brigham and Women's Hospital.

For example, proteins called thymosins maintain a pool of monomeric actin that can polymerize as needed. One type of thymosin may be involved in prostate cancer (see sidebar). The protein profilin keeps monomeric actin from polymerizing inappropriately. The protein ABP280 stitches existing actin filaments into a continuous meshwork.

The protein gelsolin breaks existing filaments into many little pieces. Gelsolin can cause amyloid deposits leading to a form of neuropathy. Finally, the protein cofilin speeds up the dissolution of filaments, in effect revving up the dynamics of the whole system, says Janmey.

All the other proteins found to associate with actin do not reorganize the cytoskeleton itself. Instead, they benefit from one of the myriad functions of this pervasive organelle. The actin cytoskeleton offers a platform for all sorts of enzymes—for example, those involved in transmitting growth signals—to meet and get close enough to their reaction partners to carry out their biochemical function.

Missing Links Between Signals and Actin

Orchestrating the dynamic changes of the actin cytoskeleton are signal transduction cascades that relay incoming messages. The dialogue that links cross-talking signal transduction pathways to the proteins making and breaking actin filaments is still poorly understood.

A hypothetical example illustrates this interplay. When a cell settles down in one location, it forms elaborate attachments. These so-called focal adhesion points are spots on the membrane where proteins gather, tying the actin cytoskeleton across the membrane to extracellular matrix molecules. During this docking process—which involves many signaling events—monomeric actin polymerizes into filaments in a local burst just under that spot. That way, a cell straps itself to a surface like a tent with the pegs firmly in the ground.

Much of its actin forms struts that run across the cell like tent poles and tie into focal adhesion points, making the cell quite stiff. But adding a growth factor that triggers certain signaling cascades will cause this cell to stir and become more fluid. Signaling events at the membrane somehow instruct the

actin-binding proteins to take apart the tent poles and reform actin filaments at the cell's edges. As a result, the membrane begins to "ruffle" and, viewed through a microscope, seems to wave at the observer.

One way scientists imagine directed motion could happen, says Janmey, is that the membrane flutters randomly. But at those ripples where growth factors have collected, these factors generate signals underneath the membrane that trigger actin polymerization. This would build a wall of actin, shoring up selected bulges and making them into semipermanent feet.

When the cell crawls in a certain direction, its cytoskeleton acts like a continuous disassembly-assembly line: the actin-binding proteins chew up filaments at the back of the cell and rebuild them at its leading edge, thus constantly recycling the cell's supply of actin.

Many of the observations that have yielded this simplified scenario were gleaned from studies of cells crawling on two-dimensional culture dishes or isolated proteins studied in test tubes. But one of the knottiest problems in understanding what proteins do in a living organism is that cells act in a three-dimensional environment. It is technically difficult to design experiments that capture a real-life scenario yet allow for the type of manipulation necessary for the scientist to tease apart complex protein-protein interactions. John Hartwig (see sidebar) has validated many in vitro findings in human platelets, but the system that most readily yields in vivo information is the lowly yeast cell.

photo courtesy of John Hartwig

A meshwork of actin filaments, as shown in an electron micrograph of a human platelet.

From Actin Arcana to Applications

Basic research into how the actin cytoskeleton manages to remodel itself almost continuously is beginning to spin off practical applications.

Flagging the Aggressor:
Known to bind actin, the protein thymosin beta15 recently rose to become a candidate marker for diagnosing prostate cancer, the most common cancer among men. A research team led by Bruce Zetter, professor of surgery at Children's Hospital, reported last December that this gene is prominently expressed in prostate tumor cells that will become metastatic, but not in normal cells or benign tumor cells. Somehow thymosin beta15 gears up the cell's ability to break free of its ties to neighboring cells, making it prone to course through the body and start tumors elsewhere. The researchers are now conducting a long-term clinical study to investigate whether this gene can help identify those prostate cancer patients whose tumors need surgery among the majority of patients who do not.

Platelets Keep Their Cool:
A potential application of actin research grew out of John Hartwig's work on the cytoskeleton of human platelets. Platelets used for blood donations cannot be stored well because refrigeration triggers actin polymerization, which causes the platelets to aggregate into clumps. Researchers are now developing a way to thwart actin polymerization. Being able to store platelets as easily as serum would have a great clinical impact, says Hartwig, associate professor of anatomy and cellular biology at BWH.

Breathing Freely:
Research into how actin filaments alter the viscous and elastic properties of a fluid may help clear the airway congestion that afflicts people with cystic fibrosis. The sticky sputum of people with this common genetic disease was long known to contain DNA. Researchers led by Thomas Stossel '67, professor of medicine at BWH, found it contains actin as well; moreover, the DNA is intertwined with actin fibers, making the sputum highly viscous. In an ongoing clinical trial in Canada conducted by the biotechnology company Biogen, patients inhale aerosols containing gelsolin, a protein that breaks actin filaments, presumably making the sputum more fluid so patients can clear it more easily.

In the long run, researchers hope to mine the actin cytoskeleton field for treatments against conditions involving unwanted cell mobility, including inflammation, metastasis and certain infectious diseases.

Rong Li

photo by Graham Ramsay

The Buzz of Wasps and Bees

This is where Rong Li, assistant professor of cell biology, has carved out a niche. Yeast deploys its actin cytoskeleton to perform a biological process that allows her to study the responsible proteins in their natural environment. When a mother yeast cell sprouts a bud, patches of webbed actin filaments appear underneath the bulging bud's membrane.

Li's approach combines the power of yeast genetics with biochemistry to speed up greatly the process of identifying genes and studying the function of the accompanying proteins. She has developed a biochemical assay that allows her to test and manipulate the function of actin-related proteins. She pokes holes in yeast cells to block the formation of actin patches in these cells' buds. Then she slips in specific proteins to see which ones can rekindle this process.

Recently Li described two proteins necessary to form the patches in vivo. One of these proteins Li had discovered earlier and dubbed Bee1, after its human relation "WASp." The WASp gene is mutated in a hereditary disease, and its protein may turn out to be one of the sought-after links between various signal transduction pathways and the cytoskeleton, much like a multisocket adapter. Though studying the complex human protein in its natural environment is difficult, Li's work is beginning to identify just what role its humble cousin plays in assembling the nimble networks of actin.

Li and other researchers, at Harvard and beyond, are quickly zeroing in on the molecular intersections between signal transduction and actin reorganization. Several local groups are working to uncover the precise role of a still-shadowy but probably crucial intermediary: a lipid component of the cell membrane. Understanding its function ultimately will help illuminate the elaborate interplay between a cell and its "outside world," in health and disease.

Gabrielle Strobel is a science writer in the Office of Public Affairs at Harvard Medical School.

Thomas Stossel, John Hartwig and Paul Janmey (l to r).

photo by Graham Ramsay

What Should I Say?

by Lisa I. Iezzoni

EVERY SO OFTEN, WE ALL EXPERIENCE fleeting moments that crystallize an essential truth about our lives. Last spring I had one, in the cramped, muffled interstices of a federal office building in Washington, DC. Before beginning a meeting of a national committee on which I serve, I had hurried to our designated cubicles to use the telephone. A man was already there. We stared at each other, with that instantaneous start of recognition. I greeted him, stating his first name correctly but mangling the last.

"Not quite," he smiled, correcting my error.

"Sorry," I said. "It's been 20 years. You taught that great course on patients' experiences of illness. It made a big impression on me—it helped me decide to go to medical school."

"I remember you well." He paused, looking at me with momentarily unguarded sadness. "I had heard about your troubles."

My mind raced—what troubles? I was instantaneously a student again, wondering what this professor could mean. Academic troubles? That would be too awful! Then it dawned on me. "Oh, you mean my MS? I don't think of that as a trouble. I'm doing fine!"

We spoke telegraphically, catching up in a scatter shot way, until I left for my meeting. During the lunch break, I rolled onto the mall below the Capitol. The day was glorious, but I could think only of the encounter with my former professor. My reaction puzzled me. Why had I not immediately understood what he meant by "your troubles"?

I knew he was shocked to see me for the first time in my wheelchair. Twenty years ago, I was constantly moving, running everywhere. I saw him tracing his memory of a physically vigorous young woman on my older face and folded body. The contrast must have been striking, but I also sensed he didn't want to show his sorrow too much. This, in turn, worried me; I didn't want to distress him. Why was I compelled to reassure him that he should not grieve for me, that I was fine?

His look, however, also conveyed admiration. Such admiring appraisal makes me uncomfortable. What could I do other than go on? The alternative was unacceptable. And, yes, it was true. My MS does not feel like a "trouble"—it is just the landscape I live in. How had I arrived at this point?

While this encounter held many layers of meaning for me personally, one aspect is shared by those of us with visible disabilities—the implicit embargo on spoken words and the volumes of unspoken thoughts and emotions that permeate our relationships with others, even a passing greeting.

Photos by Mark Rosenberg '71, a former professor of Lisa Iezzoni's, and a photoessayist and director of the National Center for Injury Prevention and Control, Centers for Disease Control and Prevention.

Communicating around disability is hard, on both sides. People often don't know what to say to us or where to look. Silence frequently becomes the paper-thin veneer over a complex tangle of fears, discomforts, sorrows, rages and uncertainties.

In other instances, similarly complex feelings prompt spoken words of many stripes—generous, healing, heartfelt, tentative, hurtful, baffling, threatening, hostile, intrusive or just plain silly. As Sally Ann Jones,* a woman in her 50s with MS, said to me:

Some people see you're in a wheelchair and immediately they raise their voice as if you were deaf. I mean, you're some kind of handicapped. They're not quite sure what to do. People aren't comfortable with handicapped people.

For those of us with disabilities, silence is often the default position. We ourselves are uncertain and uncomfortable with talking about our disability, concerned about breaching that invisible barrier that circumscribes socially-acceptable discourse. We hope that silence will insulate us from the inevitable hurt, bafflement, or stings of verbalized feelings. We think, generally wrongly, that silence protects our precious privacy.

But silence carries consequences. As Mrs. Jones said after commenting on the uneasiness of others, "In some ways, it's your obligation to kind of educate them and make them more comfortable." Silence reinforces the stigmatization of disability, the sense of shame, that disability is something to hide, that it is somehow the fault of the person with the disability. Nonetheless, opening communication around disability is difficult. What should I say? What should you say to me?

Perhaps one place to start is with examples of where communication withered or went awry—in other words, what not to say or do. I have

innumerable examples, from my own experiences and stories told to me by others.

Becoming Invisible

Those of us in wheelchairs live below the eye level of most standing adults. Nonetheless, something other than this physical fact must be at work in making us sometimes invisible. Positioned strategically in full view of such persons as clerks at shop counters or attendants checking in airplane passengers, we often remain unseen and unhelped, even after asking for assistance. Eye contact is avoided; when communication can no longer be postponed, eyes rest everywhere but our faces. I observed one particularly striking example of this powerful phenomenon involving a physician colleague, Megan Martin.

Megan had sustained a complex metatarsal fracture, and her orthopedist insisted that she stay off her foot for at least six weeks. I ran into her outside my office on her first day back at work, and she was frantic. Megan's clinical and administrative offices were a brisk ten minutes' walk apart on a good weather day, longer when the circuitous internal route was necessary. On crutches, she had just spent over 45 minutes making this trip, and she was exhausted. How could she manage the multiple trips per day that her job required? The solution seemed obvious. "Why don't you rent a scooter like mine?" I suggested. "You could ride it back and forth, and use your crutches in the clinic."

As I had expected—and fully understood—Megan's initial response was unenthusiastic. "People will think I'm a wimp," she worried. I did not argue; I was sure that they would and that it would be hard. "I'll think I'm a wimp." That was undoubtedly true, too.

"Look, Megan, it's just a suggestion. It will save you energy, make the trips quick and painless. But I can understand that you would feel strange about it." Within two days, however, Megan had rented a scooter.

Megan let me audiotape her scooter stories after the six weeks ended. She had remained uncomfortable but acknowledged work would have been impossible without it. She never felt secure leaving the building in the scooter, and so she rarely did. As she said:

You're not there. The two or three times I did take it out, it was almost impossible to get through a crosswalk before the light changed. People are crossing in front of you. I'd be sitting right at the curb, waiting to go, and somebody would just walk right in front of me and then just stand there and chat for a while. Well, they can run when the light changes. So I was just terrified. I thought, this is crazy. People don't want to see you; they're not going to see you.

I witnessed one of Megan's oddest episodes. My office door was wide open, and Megan was standing outside, balanced on her crutches, her foot newly encased in its protective boot after its six-week respite. Another doctor, Nick, a nice man whose office was nearby, came up to her.

"Megan, did you do something to your foot?" he asked.

I was stunned; Nick had been around the entire six weeks when Megan was using the scooter. Megan answered his query with equanimity, but after he left, I pounced. How could he not have noticed? Megan told me afterward that many people had reacted as had Nick—they did not appear to notice her injury or inquire about it while she was in the scooter. As soon as she resumed crutches, they asked whether she had hurt herself.

** All names are pseudonyms to protect confidentiality.*

It was amazing. It wasn't apparent what was going on until the day I was upright. And then it just hit me. Everybody knows now. Finally, they're noticing I've got a broken foot. Where were they all this time? . . . It was very striking. It went from as if I wasn't there *one day, and all of a sudden I'd come back after being absent for a month. The whole time it was really uncomfortable for people. . . . I don't know if it's a physician thing. I don't know if people can't cope—I don't know what they can't cope with! I'm going to have to see my own reaction to seeing somebody else in a scooter.*

Seen But Not Heard

Sometimes even when seen, persons in wheelchairs are not heard—people fail to accept what we say. For example, last April, after serving as a visiting professor, I arrived at the local airport to get the 6:20 flight to Boston. It was early, so I decided to check in at the main ticket counter in the lobby.

The young woman at the ticket counter met my eye. We chatted pleasantly about the unusually cool weather as she processed my ticket and wrote up the "claim at gate" checks for my wheelchair. Paperwork completed, she stepped over the opening used for passing suitcases, holding a two-inch, round, red-and-white striped sticker in her hand.

"Here's a sticker to put on your coat," she said to me.

"Why?"

"It will tell the flight attendants that you need help."

"Thanks, but if I need help, I'll ask for it," I replied.

"But the sticker helps people know you need help."

"When I need help, I will ask for it."

"So you won't wear the sticker?"

"I won't wear the sticker."

"You won't wear it?" The woman persevered, looking doubtful, unwilling to relinquish the sticker.

"No," I said. She continued to hover over me, sticker in hand. This was going nowhere. I felt an urgent need to extricate myself, to demonstrate incontrovertibly that I was capable of asking for help. I seized what seemed the most indisputable proof of my competence. In a low, controlled tone, but emphatically (I am somewhat embarrassed to report), I said, "I am a doctor at Harvard Medical School, and I can ask for help when I need it."

"When communication can no longer be postponed, eyes rest everywhere but our faces."

The woman demurred, probably terrified of getting into a public scene with an obviously speaking customer. She put the claim checks on my wheelchair; I thanked her and sped away.

This was actually the second time I had confronted the round red-and-white sticker. The first time was several years ago; I was in a manual wheelchair pushed by a colleague. An identical conversation ensued, but each time the gate agent looked and spoke to my colleague, referring to me with the third person pronoun (e.g., "Won't she wear the sticker?"). I responded directly (e.g., "No, I won't wear the sticker. I can ask for help."), while my bemused colleague stood by quietly. The denouement of that encounter went as follows:

"So she won't wear the sticker?"

"No, I won't."

"Why won't she wear it?"

I looked up at my colleague, imploring her (given her upright stature and consequent legitimacy) to put an end to this silliness. "Because it's demeaning," she said and rolled me away.

Not Asking

Many people with disabilities, however, hesitate to ask for help. We often have been proudly self-sufficient and requesting assistance is hard, again for many complicated reasons. Sometimes we are stopped by implicitly being on the lower totem of that inevitable hierarchy of human relationships. In these instances, the right thing would be for the other person to ask us what we need, as suggested by these two examples.

A colleague, Andrea Banks, told me about a recent patient of hers, a young man with progressive debility from cerebral palsy. He uses a wheelchair and is brought to appointments by his aunt. Andrea said that the first few times she examined him, she had him sit in his wheelchair and not get up on the examining table. She thought that would make it easier for him, but she never asked him if that was what he wanted.

One day the nurse told Andrea that the patient's aunt had complained, "Dr. Banks never even asked my nephew to walk to see how he does." The patient and his aunt were concerned that his walking had worsened, and they wondered how Andrea could evaluate this if she had never seen him walk. Chastened, Andrea vowed to try to have her patients walk, even if briefly, so she can see how they do. She ruefully acknowledged that additional assistance would be required to help patients with mobility impairments onto the examining table—assistance that would consume precious minutes as appointment times shorten under managed care.

During one of my core clerkships in my third year of medical school, my MS flared. I could no longer use the stairs as morning walk rounds with the attending physician traveled among the beds of our patients that were scattered across several floors. As the team entered the stairwell, I would go to the elevators, hoping one would come in time for me to catch up. If lucky, I would arrive in time to see them down

the hallway, en route to the next room.

I was still in my "tough it out, don't talk about it" mode, but it nonetheless hurt that neither the attending nor residents appeared to notice my new transit pattern and visible difficulty walking and that they did not wait for me. I also was timid—at that point, attendings seemed to hold my destiny in their hands. I did not mention this concern until the attending paused at the close of a fairly brutal exit interview at the end of his month.

"Didn't you notice I was having trouble walking?" I ventured.

"I did," he responded. "But since I understood you wanted to be treated just like other students, I didn't ask."

Saying Too Much

Just as pregnant women often find their bellies patted by perfect strangers, persons with physical disabilities are frequently grabbed, pulled, or touched by persons unknown and unasked. Generally this appears motivated by genuine, albeit unsolicited, efforts to help. Sometimes it is essential to our physical safety, as when I was lifted off a busy Washington, DC street by several solicitous strangers after my wheelchair tipped over in a pothole. Nonetheless, unrequested physical contact can be unnerving, physically uncomfortable, and sometimes counterproductive (e.g., we are pulled in unhelpful directions). Similarly, conversations can cross acceptable boundaries. For persons with disabilities, there is definitely a risk in too much communication invading our privacy—even if others are trying to be kind.

For example, late one evening during a third year, core clerkship, I was seated at the deserted nurses station completing my write-up so I could finally go home. The new resident approached me with instructions that made it obvious that he did not know about my MS and its implication: because of the risks posed by extreme fatigue, my neurologists refused to allow me to take call. I had asked the clerkship director to communicate this to my supervisors—I was shy and embarrassed about it. The resident instantly responded with a barrage of questions. What neurologic tracts were involved? Was I incontinent of urine? Of stool?

"A common thread of failed communication is that persons with disabilities are somehow invalidated: they become invisible."

Although the questions were deeply personal, especially from a stranger in a public place, I answered dispassionately, as if making a clinical presentation. I revealed that I was concerned about driving home, given the tremulousness of my legs. Apparently satisfied as to the nature and extent of my impairment, the resident led me, virtually by the arm, out the front door of the hospital and to the taxi stand. I lost a long argument. He placed me in a cab, told the driver to take me home, and instructed him to return the next morning at 6:00 AM to bring me back to the hospital. The resident paid the driver a generous sum. Despite this somewhat surreal interchange, I was touched by the resident's obvious concern.

Suspicions

Nowadays, the politics and attitudes surrounding so-called "entitlement" can filter down into individual encounters. The major contact that many physicians currently have with disability is filing forms for patients anxious to obtain dispensation for disability from the government or employers. Physicians tell me that this often makes them suspicious of patients' motivations.

Certainly, some patients do manipulate the system or are "malingerers." I, too, have given money through my car window to someone begging from a wheelchair, only to see her, through the rear view mirror, arise and push the chair away.

However, suspicions are readily communicated nonverbally, especially to persons sensitized by embarrassment about their impairments. Judgmental disbelief is hurtful. Proving that what we experience is real can become a daunting, emotionally draining, and seemingly impossible task. As Mabel Bickford, an obese woman with bad knees who uses a wheelchair, said tearfully about talking to her doctors about her trouble walking:

A lot of times I don't say anything, because if things get too out of control with my doctor, then emotionally I'm drained for the rest of the day. And when you deal with the emotional and the physical, it's hard, very hard, and a lot of doctors don't understand that. They just think it's this physical thing—that you don't want to walk. You just want to be in the wheelchair— it's comfortable. Well, you try it! I'm sure this plastic cuts my legs.

Being Invalidated

A common thread of failed communication is that persons with disabilities are somehow invalidated: they become invisible; they are not heard; assumptions are made about them; their private lives become public property; they are looked down upon, both literally and figuratively. In the most egregious examples, the invalidation is explicit, as suggested by two examples from my medical school days.

Harvard Medical School mobilizes many doctors when students become ill, certainly to ensure the best care. For me, however, one consequence was that numerous doctors with whom

I had only a passing acquaintance apparently knew many things about me. I ran into one of these physicians, Dr. Winston, in the lobby of a hospital where I was doing a rotation.

"Hi, Lisa," he greeted me in a friendly way. "It's so good to see you."

"Hello, Dr. Winston," I smiled.

"You always seem so cheerful when I see you," he said, pausing thoughtfully. "That must be one of the benefits of the inappropriate euphoria of MS. The inconvenience of MS is compensated by your always feeling happy. That must be why you are so generally pleasant."

That was definitely a conversation stopper! Any retort would be filtered though his faulty perceptions of my mental state and thus invalidated (e.g., "she's just being over-emotional — it's her MS"). Nonetheless, his comment required a response.

"Your knowledge is out-dated, Dr. Winston," I said. "Only in rare, disastrous cases of MS is euphoria an issue." I walked away plagued by a nagging doubt—is even my emotional stability and intellect under suspicion?

On my first day in the operating room during my surgical rotation, the attending surgeon let me hold a finger retractor during a delicate procedure. Once the concentrated silence was broken and closing began, the surgeon turned to me.

"What's the worst part of your disease?" he inquired.

Embarrassed by the assembled team of residents and nurses at the operating table, I replied, "It's difficult to talk about that here."

"Do you want my opinion?" he asked. The scrub nurse rolled her eyes at me in a friendly way, and knowing I had no option, I nodded.

"You will make a terrible doctor," he said. "You lack the most important quality in a good doctor—accessibility. You should limit yourself to pathology, radiology or maybe anesthesiology." He turned to address the anesthesiologist, "What do you think of this?" They continued planning my career.

"Our conversational partners feel they must tiptoe on eggshells when speaking to us."

The surgical resident barely spoke to me over the ensuing weeks, until I fell, broke a metatarsal, and started using a cane. From that point on, I was regaled with stories from attending and resident physicians about their own orthopedic injuries. Other persons with disabilities have recounted identical experiences. People find it very easy to talk to us about their broken bones! I guess broken bones are usually easy to fix—and less scary than impairments modern medicine cannot yet reverse.

Conversation in a PC Age

Finally, in the 1990s, disability has become one of those topics, like race and gender, where words matter. "Political correctness" has led to some farcical, semantic offerings (e.g., calling bald persons "follicularly challenged"). Some disability advocates focus fiercely on words, preferring, for example, "person who uses a wheelchair" to "wheelchair bound patient." While many of the word preferences have solid rationales (e.g., focusing on persons, not assistive devices), this heightened semantic concern has undoubtedly chilled efforts sometimes at conversation with people with disabilities.

Our conversational partners are afraid of offending; they feel they must tiptoe on eggshells when speaking to us. While appreciating these difficulties, I think they are quickly transcended by expressions of mutual respect and genuine interest, even if awkwardly phrased, and actions (e.g., sitting down, to be on the same eye level). As suggested by the examples of communication failures recounted above, those of us with visible disabilities have been conditioned to be "on guard."

The 1990 signing of the Americans with Disabilities Act (ADA) brought a new concern to conversations around disability—the possibility that speech conveys discriminatory attitudes and presages actions that are now illegal. In retrospect, some positions expressed to me and actions taken during my four years (1980 to 1984) at Harvard Medical School would probably be illegal under the ADA, which requires that reasonable accommodations be made for persons with disabilities. For example, late in my third year, I was beginning to think about applying for an internal medicine residency. At a student dinner, I was seated next to a senior person at a Harvard teaching hospital, and I decided to ask his advice. I would not be able to stay up all night, but few other accommodations seemed necessary.

"What would your hospital think of my situation?" I asked.

"Frankly," he replied in a conversational tone, "there are too many doctors in the country right now for us to worry about training handicapped physicians. If that means certain people get left by the wayside, that's too bad." There was silence around the table. Over the next months, after a wrenching internal debate (joined by my caring and realistic husband) and receiving little medical school support, I decided not to battle for an internship but to go straight into research.

I do not think anybody would say such things now as that hospital leader did in 1983. I have to believe that things are better for current students in a similar situation. However, while legislation can regulate actions, it cannot control thoughts. Changing pervasive societal attitudes about persons with disabilities is clearly a longterm undertaking.

What Should I Say?

Communication is a two-way street. Both partners control—albeit sometimes unequally—conversational directions and outcomes. Therefore, my suggestions address both sides.

For Persons with Disabilities

We should be sensitive to the difficulties many people have in talking to us. They are not "bad people." Often, such difficulties result from deeply-embedded, complex sources. While overly simplistic, one explanation is certainly fear. Although we cannot control our age, gender and ethnic origins—factors linked historically to prejudice and disparagement in our country—disability defines the one minority group that everyone can join in a flash.

Perhaps the most obvious stigma of disability is loss of control, over a limb or other bodily function considered essential to "normal" daily existence. This prospect terrifies Americans used to being in charge. Every day, everyone risks a life-changing, disabling injury or illness. One way to forestall this horrific possibility is to isolate or invalidate those who personify it.

Whether we want to or not, persons with disabilities are constantly teachers to those without, educating them about what our lives are like and thus what theirs might become. I take this educational role seriously, although I try to do it not by browbeating or repeatedly reminding people of my disability—that is obvious—but by just going about, living my life.

While we might aim to be understanding and patient in frustrating situations, however, total equanimity is unrealistic. Sometimes other people seem oblivious to the impact of their words or actions; saying something tart and corrective may help vent our frustration and actually improve the situation (e.g., motivate someone to move who is blocking our way). We must contend with that ever-present risk of being dismissed: "Oh, she's just upset because she's handicapped."

"Disability defines the one minority group that everyone can join in a flash."

Nonetheless, sometimes we should remember to "lighten up." Especially in casual contacts, one cannot expect to alter firmly-rooted attitudes. As often happens, we end up frustrating ourselves rather than changing minds.

Communication with physicians deserves special mention. Persons with disabilities, especially those with progressive impairments from chronic illness (e.g., chronic neurologic disease, peripheral vascular disease, diabetes), must be direct with their doctors about their functional needs. For these patients, addressing acute concerns often consumes clinical encounters and functional issues remain unaddressed. Certainly, many doctors are skilled and caring, adept at evaluating functional impairments and interceding to improve patients' lives (e.g., by prescribing physical or occupational therapy, an assistive device, or home modifications). Others, however, are not. For example, Mrs. Jones, who came to her doctor because of serious trouble walking, described how he told her she has MS:

The doctor spent about a minute and a half with me in a little tiny room, and then he said, "The bad news is, Mrs. Jones, you have MS. The good news is, when I saw you before, I wrote down three potential diagnoses in my notes. If you'd had either of the other two diagnoses, you would be dead by now." Back then he never, ever mentioned that to me. I said to him, "Why didn't you tell me?" He said, "Well, the symptoms of the other diagnoses would have been so bad, you would've had to return, and I didn't want to upset you unnecessarily." And with that, having just said, "You have MS," he left. He didn't talk to me about what to do. He didn't say, "Do X." He didn't say, "Come back in six weeks." He just left. Period. He spent about, I would say, ten minutes, beginning to end. Well, you can imagine, I was absolutely in shock. There's just no other word for it.

Part of the problem is medical education—many physicians know little about assessing and addressing functional problems. Until recently, most Harvard medical students were trained exclusively in inpatient settings where addressing acute illness, or acute exacerbations of chronic disease, was the focus. Few students ever saw patients months after their stroke, for example, to evaluate their functional progression.

Nevertheless, part of the explanation must be that doctors are people, too. Just like others, physicians experience fears, discomforts, and uncertainties about confronting disability. In many instances, we with disabilities must educate them.

For Persons Without Disabilities

My first piece of advice is to offer us choices and options. "Do you want any help?" "How can I assist you?" "I'd like to learn what it's like to use a wheelchair in Boston; is it okay if we talk about it?" "How can we change the situation to make things work for you?" "Do you have any suggestions?" "Do you want to talk about anything?" Listen, then respect our answers, even if they are a repeated, "No, thank you."

My second suggestion is for you to ask yourself a question: "Why does talking to this person make me uncomfortable?" This need not involve prolonged, internal soul searching. The most likely reasons will probably pop quickly to mind; potential solutions will readily follow.

For example, many tell me that they don't want to say "the wrong

thing," to hurt the other person. Acknowledge this openly: "Look, I'm really awkward with words; you'll have to forgive me if I say something stupid." Remember that those of us with disabilities are awkward with words, too. We are often just as anxious as you are to ensure productive communication around issues, large and small.

Thirdly, try to avoid doing what I have done throughout this article—framing the argument as "us against them." I did so here as a rhetorical device, to explicate my arguments. Nonetheless, the well-worn phrase—"we are all human" though trite is true.

The most visible feature that distinguishes you from me, perhaps, is my use of a wheelchair. Each of us, however, carries private histories that differentiate us from all others; for some of us, this one distinguishing feature is visible for others to see. For everyone, the joys and sorrows, hopes and fears that define our inner lives are invisible. Communication among people is always challenging, for innumerable reasons. Identifying the role that disability plays is the first step in removing it from that complex mix of impediments.

Finally, if words and actions are obviously caring and respectful, communication will almost always be positive. For example, at the end of my first year of medical school, I was hospitalized briefly when a bad flare made me completely unable to walk. Although I had tried to keep my situation secret, it had leaked out to some, bringing a classmate whom I knew only slightly to my bedside one night.

"Gosh," he said somewhat reverentially, looking down at me. "I hear you can't walk. You have a really serious disease." The class had just learned about MS in neuropathophysiology, and it was the time when medical students typically begin to think about their own vulnerability to disease.

"I guess so," I replied, uncertain what to add.

"Gosh," he paused again, obviously at a loss for words. He rallied. "I brought you a cheesecake." He handed me a big box and beat a hasty retreat. When spoken with warmth, even the most awkward words are wonderful.

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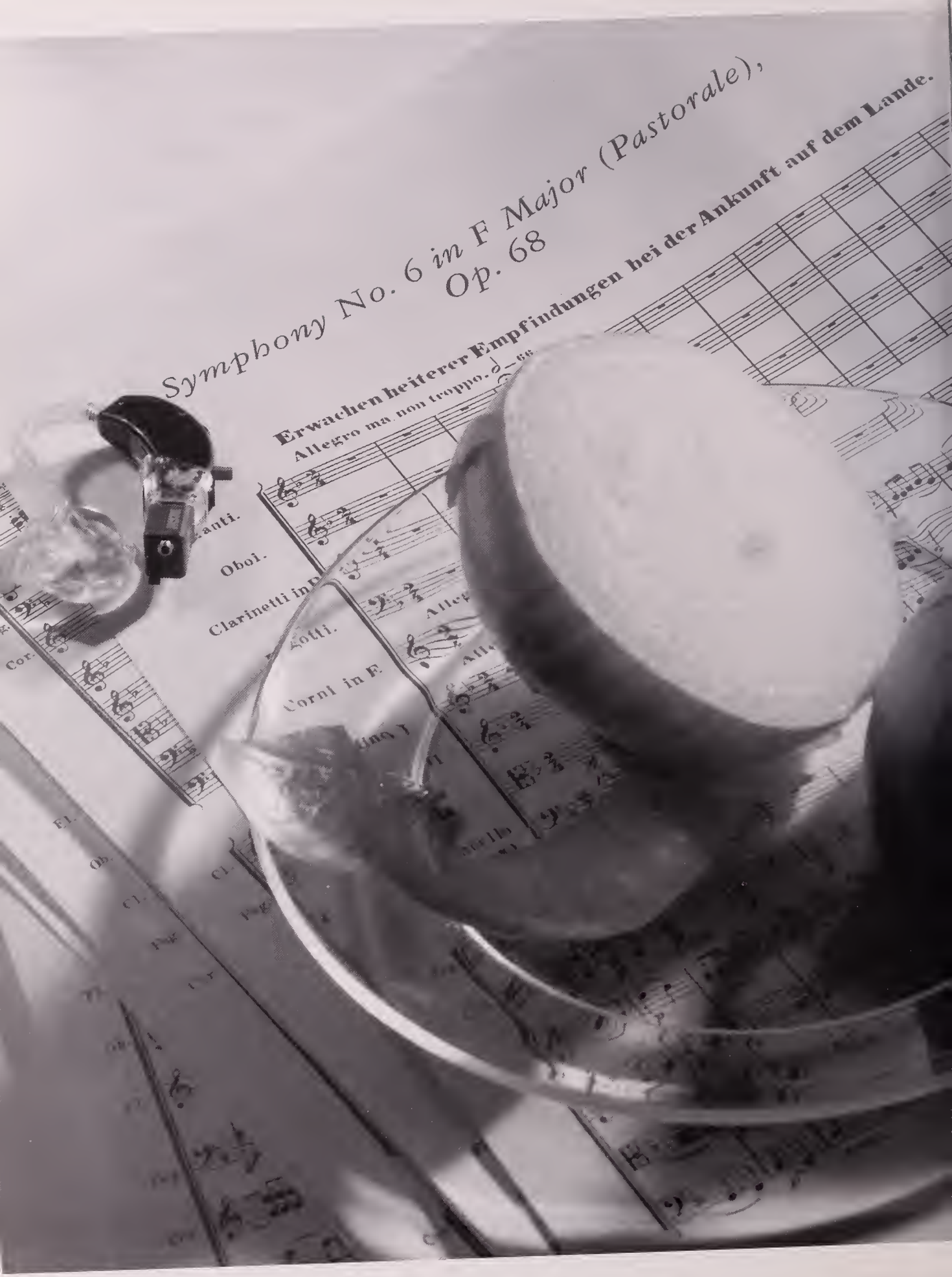
Symphony No. 6 in F Major (Pastorale), Op. 68
Erwachen heiterer Empfindungen bei der Ankunft auf dem Lande.
Allegro ma non troppo.
Oboi.
Clarinetti in F.
Corni in F.

The Song of a Thousand Cicadas

by Sanjay Gulati

photo by Stuart Darsch

FAMILY LEGEND HAS IT THAT FOR HIS spiritual health my father was advised by his guru in India to hear Beethoven's *Pastoral Symphony*. Another guru recommended a raw onion a day for longevity. I grew up nibbling raw onion and consumed by Beethoven. I knew of Beethoven's progressive deafness, the loss of his concert career, the Heiligenstadt Testament in which he contemplated suicide, and the final musical expressions of both denial and transcendence. I never expected to share anything with Beethoven, least of all the affliction that caused him such pain.

In high school, for no reason I could name, I replaced my alarm clock with a lamp connected to a timer. I developed an aversion to sitting at the back of class, and became a fixture in the front row on the right. In college my grades suddenly fell, but with a strange pattern that I did not understand until years later: I continued to do well in small, quiet classes while having difficulty with large, noisy ones.

The paradoxical experience was that advanced classes seemed easy and introductory ones hard. I thought surely I was losing my mind. Parties and group activities never felt as interesting as a quiet tête-à-tête. Yet I suspected nothing, believing that seeking intimate connection was some type of developmental phase.

It was two more years before I learned that it was an insidious gradual hearing loss that was distorting my life, slowly making a nightmare of school and making me fantasize life as a mathematical hermit. Reality struck at home one weekend when I discovered that I could feel but no longer hear the once loud ticking of an old mechanical clock.

First audiogram. I am led to a small soundproof chamber with a heavy door, like a bathysphere. Silence at first, then the slow crescendo of the tinnitus that appears when I am in a quiet place, the song of a thousand demented cicadas. Behind a panel of dials and switches, I can see the face of the audiologist as she raises the volume, obviously disappointed and increasingly concerned. Two huge loudspeakers, inches from my face, are

mute to me. I feel I am sinking through depths. The audiologist turns up the volume further, until I hear a faraway pulsing beep. I am found to have a mild to moderate hearing loss, due to otosclerosis.

Through repeated audiograms over the succeeding years, only one of the many audiologists I meet ever mentions the powerful emotions that accompany a test designed to push you till you fail. Now, I almost forgive them, knowing how hard it would be to sit with a patient and face the raw feeling of defeat.

I had been studying physics and philosophy. After failing the audiogram and being fitted with a hearing aid, my grades rapidly rebounded, but my life felt hugely changed. I lost confidence in my abilities. I dreaded the future. I was suddenly and uncomfortably aware of my mortality—it seemed that a part of my body had prematurely died. My previous stance of detached nerdiness no longer seemed an adequate answer to life. These feelings nudged me, along with the nudging of two physician parents, toward a last minute decision to forget physics and attend medical school.

First year of medical school. *Le Nozze di Figaro* with friends. We have good seats, but I have forgotten my hearing aid. Mouths are opening and closing on the stage. There is a buzzing sound that must be connected to the sawing of the violins. The flutists are urgently but silently fingering their flutes. Louder passages are musically clear but wordless. I am bored and itch to leave.

Third year, emergency room rotation. I am using my father's ancient stethoscope with oversized tubes. I clear an asthmatic child for discharge. There are no wheezes. The attending physician listens, tells me there are still wheezes, and shows me where to find them. I listen again, hard, but hear nothing. It is clear that I will not be an emergency room physician. I am losing five decibels a year, with no sign of the remission usual in otosclerosis, and

"I was suddenly and uncomfortably aware of my mortality—it seemed that a part of my body had prematurely died."

no benefit from stapedectomy.

Otosclerosis is not supposed to strike this hard, or this young. A CT scan shows dozens of foci of active disease, spicules of out-of-place bone attacking middle ears, cochleae and auditory nerves. The disease is hereditary, and my father's case is more typical: his mild hearing loss was surgically corrected and barely affected his career.

I had enjoyed my psychiatry rotation on a consultation service, and had volunteered at a crisis hotline in college after the suicide of a friend. Pathology and radiology, the only other apparent choices, seemed likely to increase social isolation. Psychiatry also offered a chance to explore the subjective world, a nice mirror image to my college interest in deeply understanding the objective one. I began telling anyone who asked, with a confidence born equally of ignorance and bravado, that I would be a psychiatrist for the deaf.

Sonia, nine years old, deaf, and profoundly developmentally delayed, ducks in and out of the bathroom, smiling hugely each time she makes eye contact. Inside she is repetitively washing her hands and running the electric hand dryer. In addition to symptoms of obsessive-compulsive disorder, she has a range of more disturbed behaviors that began a year ago, after her school bus dropped her at the wrong stop. She endured three hours of teasing by other children before the police brought her home. She knows only 22 signs. Without language, talking about the event was impossible, and she seems to have developed full-blown post-traumatic stress disorder. She understands that the bus left her at the wrong place. She does not understand that it was not supposed to happen.

Terry follows on my elbow, responding to shoulder movements that tell him 'door to the right,' 'someone's coming, move behind me,' or 'step up now.' He explores my desk with light fingers, mouthing the names as he identifies objects. To talk, I place my hands within his cupped palms. As I sign, his hands move with mine, as he mentally constructs each sign from the small part of it palpable to his hands. The communicative presence behind this deaf-blind person's hands is so powerful that it gives me chills.

Janis Cole, deaf woman, actress, language researcher and activist, is signing in a meeting. For a moment she can't recall a fact with her signing right hand. She slaps her right hand with her left, as if it were a malfunctioning television set. The gesture is so funny that the room erupts in laughter. Endless verbal creativity with a sense of humor are present everywhere in the deaf community.

Early on, I could never have imagined the pleasures I would eventually find in the world of deafness. I was for years mired in the experience of progressive loss. Despite my bold medical school declaration, I avoided deafness and deaf patients through most of residency, spending much of my time grieving in private. The symphony orchestra slowly lost its instruments, like the Haydn symphony in which the musicians pack up and walk out one by one until only a solo violin is left playing. Thankfully perhaps, with each decrease I rapidly forgot that music had ever sounded much better. Twice, when my hearing aids were replaced with more powerful models, I was astonished that footsteps, wind, and birds made so much noise. A similar

amnesia was reported by the progressively blinded man, John Hull, in his book *Touching the Rock*. For a time he remembered each person's face as he last saw it. Then he lost the concept that people have faces.

There is no dignified way to lose one's hearing. In residency I was forced to be increasingly assertive and open about my condition: Could you repeat that? Do you have an amplified phone here? Could everyone be quiet while I make a call? Would the department consider buying a new microphone for that system? (The answer, before the Americans with Disabilities Act, was "No, that wouldn't make sense just for one person.") I felt permanently seated at the back of the auditorium of life, which often seemed to be happening very far away. Occasionally, the distance would abruptly vanish in a zany or bizarre episode of mis-hearing and misunderstanding that would draw everyone's understanding my way.

I had seen my first deaf person during an early visit to an audiologist. A thin, ill-kempt man was gesturing rapidly to an uncomprehending receptionist, accompanied by guttural, ugly sounds. As his frustration and her impatience grew, his gestures became wilder and his utterances louder. The receptionist plainly wished he would go away. The horrible scene is burned in my memory. Why couldn't he speak? Would this somehow be me?

With the support and encouragement of teachers and peers, I finally began seeing deaf patients late in residency, gathering speed during my child psychiatry fellowship. Some, like the man in the audiologist's office, had damaged language skills, being in neither American Sign Language nor English. Many, when seen with an interpreter, were sophisticated people who had seen more than their share of misunderstanding by the hearing world around them. The Gallaudet Revolution, the Americans with Disabilities Act, and the play and film "Children of a Lesser God" raised the country's consciousness and caused pride to surge among the deaf. I began to lose my fear of becoming deaf. Spending more time with deaf people, I found that they had all the usual psychiatric problems, plus some special difficulties related to the most serious problem they face: acquiring signed or spoken language.

"The symphony orchestra slowly lost its instruments, like the Haydn symphony in which the musicians walk out one by one until only a solo violin is left."

Looking back to my first experience with the deaf man and the receptionist, my reaction to the scene has changed. I am no longer put off by his vocalizations. After all, they do not differ from the hand gestures that hearing people often make as they speak, often unwittingly signing something rude (to the amusement of any deaf person who sees). I also understand the man's difficulty with English. Is it reasonable to expect deaf children to learn language they cannot hear? How many hearing adults could read a book with every other word crossed out, sit in a lecture they could barely understand, or learn a foreign language from within a glass booth?

I have come to accept the model of deafness that most deaf people themselves espouse: that there is a distinctive American deaf culture, built on shared experiences and the use of American Sign Language. Along with this distinctive culture come distinctive beliefs which often differ from those of the hearing majority.

Consider, for example, the birth of a deaf child. To most hearing parents this is a tragedy of the first order, leading to intense, often lifelong grieving, self-blame and anger. To most deaf parents, the birth of a deaf child is the most natural thing in the world. In the wider deaf community, which has multi-generational deaf families at its core, it is a cause for celebration.

I believe that the grief in the first case and the joy in the second share a common root. The hearing parents are stunned by the thought of being unable to impart their native tongue to their child. The deaf parents are happy in the knowledge that their child will sign as they do. Both feelings, though opposite, recognize the crucial importance of language to our humanity.

In 1970 in California, a child was found whose parents had deprived her of language until early adolescence. Linguists and cognitive scientists were fascinated by this latest "wild" child. "Genie," as she was called, subsequently failed to learn grammatical English, lending support to Noam Chomsky's theory that a grammatical first language can only be acquired during a critical period in childhood. In the world of the deaf, apparently unknown to researchers at the time, the experiment of language deprivation in varying degrees has been a constant presence for centuries.

Charla is deaf and has no language. As a child, she was sent home after a few days of school as "uneducable." She can cook simple foods, care for herself, and perform household tasks. Sometimes she smiles, and sometimes she frowns, but we cannot know what she thinks. After months of intensive language exposure, she gets caught in a rainstorm. With an ecstatic grin she connects two signs to mean: "Wet in rain—loved it!" It is the first time she has communicated something to another human being.

José also had no formal language exposure, but his family copied and used his own invented "home signs" and he learned some elements of his country's sign language from deaf people met in the streets. In America he tries to learn American Sign Language, but will never be fluent. His nonlanguage communication, which lacks tenses, plurals and sentence structure, is termed "visual-gestural." The people who can understand him best are those with native signing skills, who show extraordinary patience in working with him.

Sandra's parents are devoted to keeping her mainstreamed in her local school. At age 15, despite above-average nonverbal intelligence, she has the English and American Sign Language capacities of a nine-year-old. Her only exposure to sign has been through educational interpreters. To her classmates, she is "special." She manages the difficulty of relating to peers through an interpreter better than most deaf adolescents. Her choice of close friends is limited to those who have learned some sign. Kept from awareness of her true language delays by caring parents and modified grading, and with no contact with other deaf people her age, Sandra believes she is doing well. As an adult Sandra will realize that she has an irremediable language delay, that she is an adult with the language of a child. She will also discover that because of her language delay she is naive about the world.

Many graduates of "oral" programs of the past, and of the mainstream and inclusion programs popular now, show deficits in both English and sign language skills, but there is little hard data about the extent of the problem. A group of British researchers performing a psychosocial study were shocked to find that of 100 orally educated deaf children (with normal brains) more than half were so language deprived that they were difficult to interview. The deficits of 17 were profound. One mother, decribing her 22-year-old son, said, "He can't really sign, but he loves his tummy. If he wants a biscuit or anything like that he'll do it (rub his stomach) or if he wants to go for a walk he'll (points at door)." That is, insufficient language exposure had induced a state of effective mental retardation.

"Language" in the past always meant only spoken language. It is now recognized that sign languages are linguistically equivalent to spoken ones."

"Language" in the past always meant only spoken language. It is now recognized that sign languages are linguistically equivalent to spoken ones. I believe that because of its essential role in psychological, social, and intellectual development, having a fluent language, any language, is the greatest need of the deaf. To experience the animation, the rapidity, and the ease of communication in sign language is to understand immediately why deaf people reject the communication solution that occurs naturally to most hearing people: to amplify or implant, and then to struggle to hear and to speak. And this solution crucially leaves out the role of language in allowing us to talk ourselves through problems, to explore our own insides and to create our own narratives.

The most extreme consequence of this inability occurs when a child with poor language is abused. Such a child lacks the language to say (to others or to himself) "so and so did such and such to me," and can develop a peculiarly powerful form of post-traumatic stress disorder, in which body memory and visual hallucinations are prominent, and there is no sense of time or place. (Psychotic deaf people, by contrast, typically experience auditory hallucinations, suggesting that the mechanism of psychotic hallucinations is hard wired to hearing.)

Stacy is in restraints again, writhing and mouthing a leather strap, once more acting out an experience of sexual abuse that occurred before she had language. Her movements are sickeningly inappropriate for her age. She avoids eye contact during each episode, thus cutting off signed communication. In between episodes there seems to be an opaque shield that prevents our getting any verbal access to the experience. As with so many other pre-lingually traumatized children, her symptoms are unreachable to treatment, and continue unabated for months.

Jack sees the walls distort into terrifying masks. He sleeps with the lights on and the door open. His waking thoughts are often intruded upon by vivid and horrifying visual hallucinations. He was physically abused in middle childhood, and had no language until late childhood. Once more, there is no verbal access to the experiences, either of the abuse or of the hallucinations. He eventually responds to extended residential placement with intensive one-to-one support.

American Sign Language is the fourth most widely used language in the country. Both the football huddle (for private signing) and baseball signals originated with deaf children. Yet it is a surprisingly invisible community, and medically it is terribly underserved; there are only a handful of physicians in America who work with the deaf. I encourage my colleagues, with open hearts and minds, to explore this hidden world for themselves.

I live now between worlds, signing well enough to feel comfortable around deaf people and to see linguistically intact patients without an interpreter. My wife and family are hearing. Many friends and coworkers are deaf. I

use an interpreter myself for groups and meetings. During the long slow decline in my hearing, some people were hurtful, but most were very helpful. So much of what I do now was created by the responsive goodwill of others.

The deaf community, a little scary at first because of its reputation for militancy, has been wonderfully inviting and supportive. Where I may have become a somewhat disconnected physicist, I have instead become a deeply involved and thoroughly fulfilled physician. It is difficult, in looking back over the journey so far, to see my hearing loss solely as loss or affliction. It has brought more into my life than it has taken away.

Sanjay Gulati, M.D., HMS clinical instructor, is child psychiatrist in the Deaf and Hard of Hearing Service at Cambridge Hospital and for the Boston Center for Deaf and Hard of Hearing Children (BCDC) at Children's Hospital, Boston. He also serves as Medical Director of the Mental Health Unit for Deaf People at Westborough State Hospital, in Westborough, Massachusetts, which is the only psychiatric unit for the deaf in New England.

Pride and Progress

by Allen C. Crocker and Ruth E. Ricker

MEDICINE HAS BEEN SLOW IN CREATING a sound, warm and accurate base for health care and fellowship for persons who are phenotypically different. I am a developmental pediatrician, long connected with Children's Hospital in Boston. Among the many professional, consumer and community organizations with which I have been associated is the New England Regional Genetics Group (NERGG), and from that numerous friendships and collaborations have come. One particularly valued relationship is with Ruth E. Ricker, an advocate working as a civil rights investigator for the U.S. Department of Education in Boston. Ruth has achondroplasia, and is a recent past president of Little People of America, Inc. She is also on the Board of the Council for Responsible Genetics.

Besides meetings and projects of NERGG, Ruth and I have worked together on the Social and Ethical Concerns Committee, and we jointly conducted a panel at a Faulkner Hospital conference on preimplantation genetic diagnosis. More significantly for me, however, Ruth has been generous in contributing to my own understanding of the views of persons with dwarfism, and to my continuing interest in learning more about human differentness. Individuals like Ruth, with humor, intelligence and high standards, press us to make better common efforts.

Ruth has an exciting new addition in her life. She traveled to Latvia this past summer, joined by her mother, to meet and bring home for adoption "Jani" (Michael Janis), a lively boy, also with achondroplasia. Boston is now richer because of his presence. It is in this context that Ruth agreed to be interviewed.

In current times, how is it for persons with dwarfism (access to jobs, community activities, etc.)?

Persons with dwarfism are more accepted and integrated in everyday life currently than even a couple of decades ago, when I was in high school. We have benefited from the disabilities laws certainly, as well as more enlightened public perception. Parents find support and information often within hours or weeks of learning of their child's diagnosis, thanks to informed medical personnel, various groups and the Internet. Dwarf children usually attend regular education classes, but have access to occupational and speech therapy, adaptive transportation and driver's education to aid them in getting the most out of their school experience.

Those of us in our 30s and younger are more likely to have college or formal vocational training than our predecessors, and therefore opportunity for a career and independence. We still find short-statured adults who are isolated—which happens with all types of disabilities—folks who never moved away from home, learned to drive or got a job. Perhaps they dropped out of high school when it got a little rough socially. They may babysit their nieces and nephews and probably haven't ventured out of their hometown.

But I think through disability rights legislation and support groups persons with dwarfism nowadays are more likely to grow up with a healthy self-image and resources, such as access to pedal extensions to drive.

We've seen a trend in our young adults in Little People of America, Inc. (LPA). Those who had been very active in LPA events as children and are now in high school and college come to very few LPA things. But this is good. They are busy with the normal social activities of being a teenager or college student. They even have after-school jobs at McDonald's. When I was in high school in the late 1970s, many of my friends worked in fast food restaurants, but I just knew it didn't make sense for me. Now many employers are used to hiring persons with disabilities and adjusting the regular job tasks to create a position that the employee can do.

Additionally, through a support group, folks have access to medical specialists who know about dwarfism. Untreated complications of dwarfism can lead to secondary conditions like hearing loss and significant mobility impairments, decreasing the likelihood of a fully integrated and independent life. I know several middle-aged dwarfs who were classified as mentally retarded when in school. They also have hearing impairments. It's obvious now that their intellect is in the normal range. They just haven't had the benefit of a decent education, or a supportive family that was empowered to question the authorities back then.

What organizations have been helpful?

Coalitions, advocacy groups and clearinghouses like the Alliance for Genetic Support Groups, National Organization for Rare Disorders, *Exceptional Parent* magazine, Human Growth Foundation, Billy Barty Foundation and, of course, LPA.

LPA is a genetic support group with a membership of 6,500, comprising primarily individuals with dwarfism and their families. For 40 years it has been led by adults with various forms of short stature. LPA is probably unique in that it was founded by affected adults, like some disability rights groups, and unlike other genetic support groups, which are often formed by parents and medical people. One of the real beauties of LPA is that it always has had affected adults and families together. Growing up in LPA, I knew lots of dwarf adults as friends and role models. And my (average size) brother and parents certainly benefited from this too. I think it's great for us dwarf adults to get to know families of dwarf kids, to understand their issues. Plus, many dwarf adults have children too.

In recent years, there's been a gradual expansion in power-sharing in the organization as the dwarf membership has become increasingly sophisticated and confident. There's no chance that average size parents could take over the group now, which would easily have happened when I was a kid. That would not have been a hostile takeover, but just that people with experience in other organizations are natural leaders. Average size parents now have full voting rights, and two of thirteen current district directors are average size parents. We've just evolved to that.

The membership is diverse in background, profession and disability. However, there is a common feeling of self-acceptance, pride and community that has been compared to more traditional disability groups and the deaf community. The concept of a dwarf community is illustrated in part by the dozens of dwarf children from all over the world adopted by LPA members.

However, perspective on the idea of community is different for the 90 percent of people with short stature who are not involved in LPA, whose membership denotes a self-selection or identification process. Some short statured people are part of the larger disability community and not the LPA. Dwarfs and other persons of short stature vary as to whether they identify as having disabilities. This seems to be in transition. In younger people who have been able to benefit from disability rights legislation, there is more comfort and identity as people with disabilities.

Are there new genetic discoveries of relevance?

The gene for achondroplasia, the most common type of dwarfism, was discovered in 1994. Achondroplasia is caused by a gene mutation that is the same in 98 percent of instances. The mutation affecting growth, especially in the long bones, occurs very early in fetal development in 1 out of every

20,000 births. Since the achondroplasia gene discovery, genes for many other forms of dwarfism have been located and identified, including those for spondyloepiphyseal dysplasia, diastrophic dwarfism and pseudoachondroplasia. These discoveries occurred much more rapidly than either the members of LPA or the medical community had anticipated. Suddenly and unexpectedly, LPA was placed right in the middle of the medical, social and ethical debate surrounding the brave new world of genetic technology. At that time, formal discussions and education on genetic issues had not yet begun within LPA. Most of us, like most of society, had limited knowledge about the Human Genome Project and the social and ethical implications associated with the possible applications of genetic technology.

On one hand, the breakthrough may be used to help achondroplastic couples identify a fetus with "double dominant" or homozygous achondroplasia, a fatal condition that occurs in 25 percent of births to those couples. But it is also possible that the tests for genes causing short stature will become part of the increasingly routine and controversial genetic screening given to all expectant mothers, ultimately with eugenic implications.

LPA's task is public education, so that people of all sizes, including potential parents and health care professionals, will be properly informed of the realities of life with short stature.

Changing the subject, how did you learn about Jani?

Growing up in LPA, I just knew one or all of my children would be adopted. OK, I assumed I'd get married too, but when that had not happened by my mid-30s, I went ahead. LPA has an adoption coordinator, a member who serves as liaison with adoption agencies and professionals. She sends mailings about LPA to them, asking them to notify LPA when they have a child with dwarfism available for adoption.

Ruth Ricker and Jani

These days most kids we hear about are in other countries. Actually, we are a victim of our own success, because in the domestic adoption arena dwarfism is no longer a condition that makes a child "hard to place." So the majority of the dwarf kids being adopted today are from Russia, Korea, India and Latin America, where our kids, like all children with disabilities, remain more difficult to place.

I saw Jani's picture in LPA's national newsletter in a photo-listing of dwarf kids available for adoption. He's six, in the age range I thought made sense for me as a single working parent, and he looked adorable, of course. At that time, I didn't even know where he was; I'd assumed it was Russia. When I contacted the U.S. adoption agency representing him, I learned he was in Latvia. Then I started boning up on the Baltic region. I found someone in a neighboring office at work who is active in the local Latvian-American community, and she's been a great resource.

Can you tell us about his life up until now?

He'd been in an orphanage since he was 2 or 3 years old. It looked like a nice, homey place when my mother and I went over in August. The staff definitely cared about him. I don't know how accepted he was by the other kids. He doesn't seem very nostalgic looking back at the pictures from the place. They gave us the oak leaf laurel that he wore on "Jani Day," which is celebrated on the summer solstice in Latvia, and they showed us pictures of that, as well as other special occasions.

When I asked them if he'd had any

ear infections, saying it was common in dwarf kids (as well as in orphanages, but I didn't say that), they said he'd had one. Well, when we got to the hotel I could see and smell one in his ear. It's taken two months to get a handle on it. He bonded almost immediately with me (and Grammy), so he didn't have those kinds of attachment problems often seen with post-institutionalized kids. Latvia's Ministry of Justice, which oversees adoption, has decreed that adoptive parents not have contact with the other children, to protect those children from the pain of parents adopting someone else and not them.

I enjoyed visiting Latvia. It is a beautiful country with a fascinating history. Jani was born a month after the final stage of the independence from the Soviet Union. As rich as the heritage is, and as much as they love children, as in many cultures people with disabilities have a harder time. It's normal in a society where the majority of the population is economically deprived.

The first day I had him, we were walking around Riga, the capital, and a kindly gentleman pressed two coins into my hand and gestured to Jani, smiling. I have friends in the disability community who've been handed money on the street, but it never happened to me in the U.S. I think that symbolizes the difference.

I want to keep as much of his Latvian vocabulary as possible, and we'll be plugged into the Latvian-American community here in the Boston area. Most of his medical people are at the Floating Hospital at New England Medical Center, but he has a Latvian pediatric dentist. Now there's a coup. She's been great.

How do you foresee his future? Where are we as a culture going?

I'm optimistic about his future. Maybe he'll work for the State Department, UNICEF, or become an international business tycoon. I really hope and pray that the genetics engineering stuff doesn't go too far. Public perception of dwarfs and other people with disabilities could be affected by this . . . as our kids grow up, socialize, try to get jobs. This will erase the progress we've made recently in the U.S. with the disability rights laws and increased integration and acceptance.

How can physicians, medical facilities and insurance plans be more supportive?

Not unlike our disabled sisters and brothers, we need medical people to have accurate information. Parents are still sometimes given wrong messages. Families need information to be conveyed in a sensitive, objective manner—during prenatal testing, ultrasound exams, and later when the baby is born and diagnosed. How medical professionals handle these situations has a major effect on the parents' feelings and approaches toward the children and their potential differences.

Further, it is important for medical professionals to be willing to consult with specialists familiar with dwarfism when something comes up that they aren't familiar with, and if necessary, to refer the family (or adult with dwarfism) to such a specialist, even if they're out of "the network." We have members who've survived botched neurological surgeries by persons inexperienced with dwarfism, and some who didn't survive. And some practitioners haven't been aware of breathing concerns in young children, special anesthesia issues, or that most of our kids look like they have hydrocephalus, but really don't.

A great resource for families and medical professionals is the article "Health Supervision for Children with Achondroplasia" in the March 1995 issue of *Pediatrics* (95:443-451). LPA's medical advisory board members are a fantastic resource for affected adults, parents and health care professionals as well.

Allen C. Crocker '48 is director of the Developmental Evaluation Center at *Children's Hospital, Boston, Massachusetts.*

Ruth E. Ricker is a civil rights investigator for the U.S. Department of Education in Boston.

Information on LPA can be accessed by calling 1-888-LPA-2001 or at http://www-bfs.ucsd.edu/dwarfism.

A Full Life

by Ellen Barlow

The survival of more children with intensive disabilities has created other levels of challenge for their families, physicians, schools and communities. At the heart of this challenge is that despite the obstacles, all children are "owed a life as full as possible," says Judith Palfrey, the HMS T. Berry Brazelton Professor of Pediatrics.

One community focus of Palfrey's Division of General Pediatrics at Children's Hospital is on the world outside the ICU where medical science is triumphing: what happens to the children with complicated health care needs when they go home from the hospital? Palfrey and her colleagues have applied the tenets of family-centered integrative care to projects in the school setting, in pediatricians' offices, and with residents training to be pediatricians.

Their first project arose in the aftermath of the Education for All Handicapped Children Act of 1975 (since 1990 called the Individuals with Disabilities Education Act), which entitles all children to free educational services through the public schools. Schools have opened their doors to students with a range of special needs, including those who depend on medical technology to survive: supplementary oxygen, tracheostomy, respirator, suctioning, gastric feeding, central venous line, ostomy, urethral catheterization or dialysis. Project School Care was started at Children's in 1986 to more precisely define this population of children and to provide the health information schools and families need to assist them.

They published guidelines for care, which became a model for other states, and they continue, in collaboration with the Massachusetts Department of Public Health's Technology Assistance Resource Team, to provide child-specific consultative services.

"We go in as a facilitator to ensure that every child has the opportunity for an educational experience," says Stephanie Porter, MSN, RN, the coordinator of Project School Care and director of clinical services at the Institute for Community Inclusion, the umbrella organization over many of the Division of General Pediatrics programs. For example, Porter had a recent meeting at a middle school about a 12-year-old girl with chronic lung disease who is awaiting a lung transplant but whose health is rapidly deteriorating. Porter, the girl's mother, the headmaster, school nurse, her case manager, and her HMO manager all met to discuss such things as the girl's changing daily needs, the necessity of an aide or a nurse to be with her, and the emergency plan.

"The school nurses are usually great and are involved in caring for these children, but because of funding issues they are often caring for 1,200 or more children and/or covering multiple schools," says Porter. "But the benefit is that being in school with their peers improves the quality of life for these children."

Focus groups have helped guide the direction of Project School Care's efforts. As a result of a parent focus group, a resource booklet for the families of children with disabilities and special health care needs was compiled. Now Porter is organizing a focus group of the children themselves to learn whether their school experiences have been beneficial: have they developed friends and been accepted? Are there any changes they'd like to see or reactions they'd like the teachers, principals and school nurses to know about?

"Our focus is always the families and the children," says Porter. "They are the experts on what they need."

That focus is often sorely missing from the education of physicians, whose training is more typically organ-specific, says Palfrey. This year, monthly home visits will be incorporated into the training of pediatricians at Children's. Once a month residents will be guests in the homes of children who have chronic illnesses or disabilities. "The tables will be turned and the residents will be the guests," says Palfrey. They can witness the family dynamics and challenges these families face in ways just not possible during an hospital or clinic visit.

Some of these challenges, for example, are that specialized care and supportive services are fragmented, medical records aren't centralized, and what the children need is often buffeted by such forces as what is reimbursable. "Simple problems are often handled in a complicated way because no one provider or provider team steadily cares for the child and stays in contact with the family," says Lisa Sofis, project manager of the Pediatric Alliance for Coordinated Care (PACC), a consortium of six community-based pediatric practices that has been designed to rectify this with integrated, coordinated care of children with special health care needs and their families.

courtesy of Project School Care, Children's Hospital

PACC was initiated and is administered by Palfrey's Division of General Pediatrics, in part to also anticipate the increasing role of managed care. "By dint of the way managed care is going, community-based pediatricians and physicians are being asked to take care of everyone in their panel and do it as cheaply as possible, which means you can't always refer to subspecialists," points out Palfrey. "We're trying to keep a balance of integrated care between what they can do and do well and what we at a tertiary care center can do and do well for families."

A pivotal aspect of the program is that PACC families work closely with not only a pediatrician but a nurse practitioner, who makes home visits when deemed appropriate. A home visit may seem expensive, but Palfrey tells a story that she says highlights the preventive health value of these visits and their role in decreasing costs in the long run.

One NP did a home visit with a diabetic boy who lived with four siblings and his mother in an apartment. The NP did a physical exam of the boy and in asking other questions found that there was no needle box; after giving him his insulin, needles were thrown in the rubbish. A two-year-old sibling had once stepped on one of the lances used for testing his blood sugar. Insulin was not being stored appropriately and was kept on top of the cable television box.

"The nurse rigged up a detergent bottle with a small opening for the needles and on a subsequent visit found all these problems corrected," says Palfrey. "The boy's diabetes is now in better control. We've learned things the doctors didn't know by the NPs being more global in their assessments."

An Individual Health Plan is created for each child, a road map for the health care and services he or she will need at home and in school. That information is centralized at the community clinic but shared with school staff, families, medical specialists or other providers of care. Data are being collected to monitor hospital utilization and costs, family satisfaction, and health status of the child.

Besides reducing fragmentation and duplication of care, one hope of PACC's planners is that the inconsistencies in reimbursment policies that come to light might reveal ways to provide more efficient and less expensive care. One example: IV poles cost only $20 to purchase but because only rentals are reimbursable from Medicaid or most insurers, they cost $100 per month.

"One of the other things we're showing with PACC," adds project manager Sofis, "is that pediatricians with the right tools can make decisions about the when, who and where of referrals when appropriate and weave the thread of care themselves." PACC participants too are finding that health outcomes are better if the family's needs are addressed and they are involved in the treatment plan.

Among disabilities' rights groups, self-determination is a central concept that Palfrey says they are also mindful of. In her years of involvement in this area, "I have absolutely seen attitudinal shifts in terms of individual rights."

Advances in medical technique and technology have meant there are many more children with disabling conditions to care for—depending on the definition of "special health care needs," one to fifteen million children. But fortunately, too, Palfrey is seeing an influx of medical students and pediatric residents interested in the kind of integrative care approach in the community that they have been doing. "It's really exciting to see more house staff who have really thought about what kind of pediatrician they want to be."

Stephanie Porter has also seen more supportive attitudes evolve in the schools and community, particularly since 18 years ago when her daughter was born prematurely at 25 weeks. "Generally, there's been a whole evolution of family-centered care across the country, more families involved in policy-making, more resources for parents to turn to, more collaborations with state agencies," Porter comments. "But I suppose it's the small steps where we really see the change, improving the lives of individual children." Her daughter is a testament to that: though she dealt with complicated health problems as she was growing up, she is now a confident teenager in her freshman year of college.

Ellen Barlow is the editor of the Bulletin.

Struck by a Stroke

by Hilary Siebens

"I CAN EQUATE THE LOS ANGELES earthquake with my stroke. It happened so suddenly and I had no control." This was the analogy one Californian stroke survivor brought to a support group. One is "struck suddenly with violence," as the first term for stroke, apoplexy, means in Greek. It is in the wake of such an event that rehabilitation medicine tries to make a difference. Slowly, over the last ten years, the evidence is growing that rehabilitation efforts are succeeding in ways never available earlier this century or before.

Historically, writings about stroke did not refer explicitly to the rehabilitation process. The closest of Hippocrates' aphorisms is: "It is impossible to remove a strong attack of apoplexy, and not easy to remove a weak attack." In 1839 the first American edition of the British medical textbook by Marshall Hall, *Principles of the Theory and Practice of Medicine* (edited by Jacob Bigelow and Oliver Wendell Holmes), makes brief mention of apoplexy and general paralysis and has little on treatment and rehabilitation.

In this century, in 1961, Howard Rusk co-authored with Irvine Page and Michael De Bakey, among others, an interesting book, *Strokes: How They Occur and What Can Be Done About Them*. In his chapter, Rusk observed that until a few years earlier patients with hemiplegia had been viewed by physicians with hopelessness and helplessness. They were placed under custodial care with families or in nursing homes. This is substantiated by an additional report in 1976, the first U.S. Department of Health, Education, and Welfare's Stroke Care Guidelines.

"There still exists on the part of the healthy an embarrassment in the presence of the afflicted patient whose mark of a stroke is usually obvious . . . the sufferer from other equally serious diseases is usually not the object of such ostracism. . . . As late as the 1950s the emergency room physicians of some hospitals determined whether or not a stroke patient could swallow adequately. If he could swallow, he was discharged . . . told nothing could be done. If he could not, a nasogastric tube was inserted and he was discharged . . . nothing to be done."

The second U.S. government publication on stroke rehabilitation was published in 1995 through the Agency for Health Care Policy and Research (AHCPR). I had the "once in a lifetime privilege" of serving on the expert writing panel of those guidelines,* from my perspective as an internist, geriatrician and physiatrist (an MD trained through a residency in Physical Medicine and Rehabilitation). It is perhaps also relevant that I have the perspective of a woman physician. (I often wonder if being a woman was a factor in my choosing a formerly "fringe" but very patient-focused field of rehabilitation. Clearly rehabilita-

tionists, both men and women, by their nature must focus on the emotional suffering of patients and their families and be comfortable doing this.)

The national guideline project was part of AHCPR's congressional mandate to develop, in a systematic way, clinical guidelines for health care providers based on research evidence. Two of the twenty or so guidelines—cardiac and stroke—focused solely on rehabilitation. We worked for over two years on the project. Our team of experts were opinionated, vocal, had senses of humor, and could occasionally be convinced to change an opinion. One prominent member, for example, boldly stated that no patient with dementia and a new stroke should receive rehabilitation. The opinion shifted, reasonably, when confronted by the opposing view that dementia absolutely did not preclude rehabilitation—it all depended on the degree of dementia and whether the patient could still learn and cooperate with supportive staff.

The Post Stroke Rehabilitation Guidelines touch on the huge array of issues that must be confronted by patients, their families and health care professionals. The clinical problems go beyond the model for thinking about patients that many of us learned in medical school. Our usual construct includes a straightforward organization of information: history of present illness, past medical history, social history, review of systems, physical examination, laboratories, and assessment and plan. The review of systems was generally organized along organ systems, and nowhere in these categories does the patients' functional and emotional status fit logically. For example, what about depression and anxiety? What about wheelchair use? What about desire to work?

Rehabilitation has its own set of definitions that guide the thinking and treatment planning for patients with disabilities. The most widely known definitions are those for impairment, disability, and handicap through the World Health Organization in its International Classification of Impairment, Disease, and Handicap (1980). Impairments are losses or abnormalities in physical or psychological capacities, usually conceived of at the organ level (below the knee amputation). Disabilities are disorders at the person level and represent a restriction in performing an activity in daily life (inability to walk without a prosthesis). Handicaps reflect issues at the societal level and functional limits (inability to walk up stairs with a prosthesis with no elevator access).

The construct rehabilitationists use for patients progressively expands from the cellular/organ level of disease to the mental and physical functioning of the patients to how patients are functioning in their living environment. This complexity, along with the huge variation in location of strokes

New Kid on the Block

"We're a young department and we like that," comments Walter Frontera, director of the HMS Department of Physical Medicine and Rehabilitation. Although the department is just over two years old, its origins go back to 1981 when the HMS committee on rehabilitation, led by Clement Sledge, recommended the creation of a division of rehabilitation medicine.

Yet 10 years would pass before this became a reality and academic status was granted to the rehabilitation program at the Harvard-affiliated Spaulding Rehabilitation Hospital. In 1992 Paul Corcoran, who had been chair of Physical Medicine and Rehabilitation (PM&R) at Tufts-New England Medical Center, became the interim director for the division and in 1993, the residency training program was approved, with four residents accepted in July of that year.

During the hunt for a permanent director, the search committee took the further step of recommending that the new director head an independent academic department. Finally in 1995 the department was established, with the pre-existing division remaining multidisciplinary. In 1996 Corcoran retired and Frontera took over the directorship just as the first four residents were graduating from the program.

As it currently stands, the department consists of academic faculty who have training and certification in PM&R, while the division is open to any Harvard University faculty member who works in the field of rehabilitation, providing services, teaching or doing research.

As Frontera, HMS associate professor of physical medicine and rehabilitation, observes, there are benefits to being the new kid on the block. "We have an opportunity to develop a new department because we are starting from nothing. I welcome that, and HMS and Spaulding have both been supportive in helping to implement a multi- and inter-disciplinary approach."

Physical medicine and rehabilitation was first recognized as a medical specialty by the American Medical Association in 1938, and the American Board of PM&R was founded in 1948. Frontera points out that for many years rehabilitation was considered to be important only for a small patient population. This has changed in the last 15 to 20 years as the number of conditions that can be helped by rehabilitation services has expanded.

The types of conditions that now benefit from these services reflect the multi-disciplinary nature of the specialty and include cancer, stroke, spinal cord injury, traumatic brain injury, cardiac and pulmonary problems, orthopedic and pediatric conditions.

and clinical syndromes, has been aptly described by C. Miller Fisher, a pioneer in stroke research at the Massachusetts General Hospital, in his forward to Louis Caplan's excellent text, *Stroke—Clinical Approach*: "No two stroke cases are the same, and we are reminded of the observation of a London Cockney that 'there ain't more than one average Englishman in a hundred'."

Another key factor in rehabilitation is time. Our time frame as we assess patients involves processes that occur over weeks, months and years. This is one of the most easily articulated differences between rehabilitation and treatment of acute medical or surgical conditions. In the acute care hospital, physicians must focus on pathophysiologic processes that affect the patients over seconds (cardiac arrhythmia) to minutes (progressive hypoxia) to hours (worsening pneumonia). In rehabilitation, we generally don't have to deal with life-threatening medical instability. Instead, we work with recovery processes occurring over days, weeks and longer. For patients with stroke or other types of brain injury, recovery happens at many levels: from alterations in biochemical processes to alterations in family structure to alterations in the environment.

One way to organize the incredible growth of information in this huge subject area is to consider four key domains which are part of a concept I've called the Universal Longitudinal Patient Care (ULPC) Pathway (©Siebens 1996). This ULPC model is being developed as a tool to teach medical students, residents and others how to best approach any patient with disability and how to best organize treatment priorities. These domains are: Medical/Surgical Issues, Mental Status and Coping, Physical Functioning, and Living Environment (physical and social).

As this model applies to stroke, the first "medical/surgical" concern must be stroke prevention, both primary and secondary. Progress has occurred in prevention; those of us physiatrists committed to stroke rehabilitation would like nothing more that to be put out of work, just like the rehabilitationists who were once committed to the rehabilitation of polio survivors.

Recent trials have demonstrated that Coumadin prevents strokes in patients with atrial fibrillation. Treatment of hypertension is associated with a lower risk of stroke. Studies in secondary prevention show that smoking cessation, and treatment of diabetes and hypertension decreases expected mortality and stroke recurrence during the first five years following a first stroke.

In severe strokes, the physician's first "medical" decision is whether or not treatment should be withheld. This decision usually arises when it is clear that the patient cannot swallow due to obtundation or poor arousal in addition to severe hemiplegia. A deci-

Likewise, it is not only physiatrists who are involved in patient care. "Our division is made up of members of a wide variety of specialties," says Frontera. "For example, we have a faculty person with a PhD in rehabilitation engineering. This is a field where it is important to keep the doors open."

While the research interests of the faculty cover many aspects of physiatry, much of the research being conducted in the department is within several laboratories. The Gait Laboratory was created in 1992 and includes sophisticated equipment to measure joint and limb segment kinematics and kinetics during activities for both clinical and research purposes. Research has focused on defining useful gait parameter measures and on better understanding the relationships between impairments and gait disabilities.

The Muscle Cell Physiology Laboratory was begun in 1996 and includes equipment to assess muscle cell anatomy and function. Research is focused on evaluating muscle cell function in the elderly or in the presence of disability. There is also the Assistive Technology Center which was started in 1994, providing access to state-of-the-art equipment to help with mobility and activities of daily living.

Although Spaulding Rehabilitation Hospital is affiliated with Partners, the alliance between MGH and Brigham and Women's hospitals, the department of PM&R is Harvard-wide. And the department's mission, says Frontera, is to develop PM&R throughout the Harvard system. Thus, he and his colleagues have initiated a series of presentations to some of the other teaching affiliates, such as Beth Israel Deaconess Medical Center and Children's Hospital, to propose a service and/or department within each of these institutions. "This is another way for us to build bridges to promote inter-institutional projects."

Currently there are 23 residents in the department, with four following a combined track—another symbol of the collaboration between PM&R and other departments. Several of the faculty have combined training in internal medicine, pediatrics or neurology.

As the field of PM&R continues to grow, Frontera posits three questions that will determine what changes will be seen in the years to come: "How do we organize services to those patients who need it? How do we train and educate everyone involved in the rehabilitative care of these patients? And how do we develop and conduct research so as to understand patient needs?"

Janet Walzer

sion needs to be made whether a nasogastric tube should be inserted early and/or a gastrostomy tube placed later on.

These patients often have been suffering from a progression of worsening disabilities before the stroke. They may even have been nonambulatory and gravely cognitively impaired. An article last fall in the *New England Journal of Medicine* sensitively reviewed the issues around managing this difficult decision of withholding feeding tubes. At a national level, the increased public education about advance directives may also prove helpful to this decision-making process.

Another area of improvement in stroke care is a 28 percent reduction in odds of death occurring in the first 17 weeks post-stroke if patients are treated in specialized stroke units rather than in general medical hospital units. This meta-analysis by Peter Langhorne and colleagues showed further that this decreased percentage in the odds of death persisted (21 percent) at 12 months after the stroke. The reasons are not totally clear but probably include the fact that stroke patients have enough specialized life-threatening problems (dysphagia with aspiration, pneumonia and dehydration, deep venous thrombosis, urinary tract infections) that treatment by a group specifically interested and experienced in these problems can achieve better survival. This particular study could not evaluate functional outcomes since data were not collected uniformly.

Acute stroke care in hospitals can be improved by applying organized stroke treatment pathways. Hospital staff identify key elements of care and implement their routine use. Ib Odderson and colleagues, for example, published a stroke pathway that included standardized admission orders, swallow screen on day 1, therapy and social work evaluations day 2, physiatry consultation day 3, if indicated, and by day 4 discharge date and location established if possible.

Urinary tract infections were decreased significantly by removing foley catheters early and managing voiding problems differently. Something as simple as preventing a urinary infection can make a significant difference to patients already struggling with the horrible effects of the stroke. In addition, the pathway was associated with a decrease in hospital length of stay from 10.9 to 7.3 days. From the rehabilitation perspective, this shortened stay is likely to get a patient into the rehabilitation setting quicker, generally an advantage provided all acute medical issues have been resolved and appropriate rehabilitation planning has been done.

The domain "mental status and coping" encompasses a number of potential serious problems for stroke patients. Depending on the stroke location, mental status can be severely impaired or not impaired at all. A single focal [lacunar] stroke from hypertension may cause arm or leg weakness without affecting mental status. Whereas several years ago cognitive problems like delirium would go undiagnosed, now there is much greater likelihood that cognitive problems in stroke patients are more actively addressed.

Depression can be another problem days to weeks after a stroke and correlates with poorer functional levels. As described once by a physician who himself developed depression and was successfully treated, "Having depression is about as comfortable as having rabies." Patients with depression feel terrible and we need to diagnose and treat the condition very aggresively.

The array of medications available to effectively treat depression has significantly improved. Older stroke survivors often can tolerate, with fewer side effects, the newer serotonin-reuptake inhibitors. Interestingly, the psychostimulant methylphenidate (Ritalin) used to help treat depression is closely related to amphetamine. Amphetamine has been found to enhance motor recovery in rodent models. At Spaulding Hospital our Department of Physical Medicine and Rehabilitation (Joel Stein and others) and the Department of Neurology (Jill Kaplan and others) are collaborating on a randomized control trial to investigate the use of methylphenidate to enhance motor recovery.

Many studies are now under way to evaluate "physical functioning" and its recovery after stroke. This was not feasible fifteen, even ten, years ago because researchers had not yet developed standardized measures of functional performance that could be easily used in different settings. Also, computers were not readily available to help track and analyze the huge amount of data. Through the leadership of Carl Granger and the American Academy of Physical Medicine and Rehabilitation, a standardized measurement tool, the Functional Independence Measure (FIM)™, was developed and is now used widely in rehabilitation hospitals and some skilled nursing facilities to assess basic physical functioning like toileting, dressing and climbing stairs, as well as some cognitive functions like problem-solving and social skills. Various rehabilitation approaches can now be more rigorously assessed.

The patient's "living environment" domain must also be considered in stroke recovery. This includes the physical environment (does the patient live on the street or in a three-story walk-up) and the social environment (intimate relationships, family, friends). The social environment is especially critical after stroke since help may be needed for personal care (like bathing) and/or homemaking (preparing meals, shopping). For persons living with family, the family can be educated and trained to help provide care. In the absence of family or friends to help out, living in a nursing home either short- or long-term is the best solution if personal care is required.

The stress on families providing the caregiving can cause them to

become depressed and "burnt out." Successful interventions to improve family care are now being systematically defined. In one study by Ron Evans and colleagues, education of the caregiver—teaching him or her how to react to and manage difficulties—led to both better caregiver mood as well as better function in the patients themselves. Caregiver support groups are also beneficial. Stroke support groups in local communities are finding local philanthropic support to provide this crucial care and education which most acute medical centers do not provide.

Specific components of the rehabilitation process—treatment of depression, gait training, caregiver education—have been identified as important components for better physical and psychological outcomes. A growing concern is where this type of care is provided most cost effectively, as health care payment mechanisms shift from fee-for-service to capitated programs with different financial incentives.

Stroke rehabilitation starts in the acute hospital and continues in several settings: acute rehabilitation hospitals with 24-hour physician coverage and the full complement of rehabilitation personnel (psychology, speech, nursing, physical and occupational therapy, rehabilitation physicians); skilled nursing facilities with generally fewer rehabilitation personnel available; outpatient rehabilitation services; and home health services. Recently, managed care organizations have shown preference for the less costly skilled nursing facilities (SNFs) rather than inpatient rehabilitation hospitals (IRHs) because no data existed to show that the more expensive rehabilitation leads to better results.

Health services research is examining more carefully the issue of sites for stroke rehabilitation. A recent study confirmed that six-month mortality is no different for stroke survivors treated in skilled nursing facilities compared to rehabilitation hospitals. However, another study published in the *Journal of the American Medical Association* last January by Andrew Kramer specifically evaluated functional outcome in 485 stroke patients admitted to skilled nursing facilities and inpatient rehabilitation hospitals. Outcomes were adjusted for those factors known to affect return to living in the community and levels of functional recovery.

This study documented significantly better functional outcome (more patients returning to community residence, more recovery to pre-stroke function in activities of daily living) in the IRH programs. Cost and resource use were greater in the IRHs, but the added resources achieved better outcomes. The clinical and financial challenge now is to determine which elements of the more successful acute rehabilitation hospital programs are essential and if these better results can be achieved at lower cost.

There are signs that the cost of inpatient rehabilitation is decreasing as length of stay decreases—without decrements in functional improvements. The worry, however, is whether any increase in family caregiving is leading to any increase in family problems.

Research is also starting to evaluate "quality of life" in stroke survivors, assessing how they feel they are doing. One study identified depression, social support, and functional status as predictors of quality of life. Another survey that asked patients to rate their health status revealed that even mild strokes negatively affected similar predictors of quality of life. Without this type of thoughtful measurement, patients with mild stroke may miss out on helpful interventions.

The hope is that ongoing biomedical research will lead one day to the eradication of strokes altogether. In the meantime, the components of stroke rehabilitation are receiving more systematic scrutiny uncovering better rehabilitation approaches. May our new Department of Physical Medicine and Rehabilitation at HMS, in conjunction with other departments, also contribute to this important process. At the very least, we have started.

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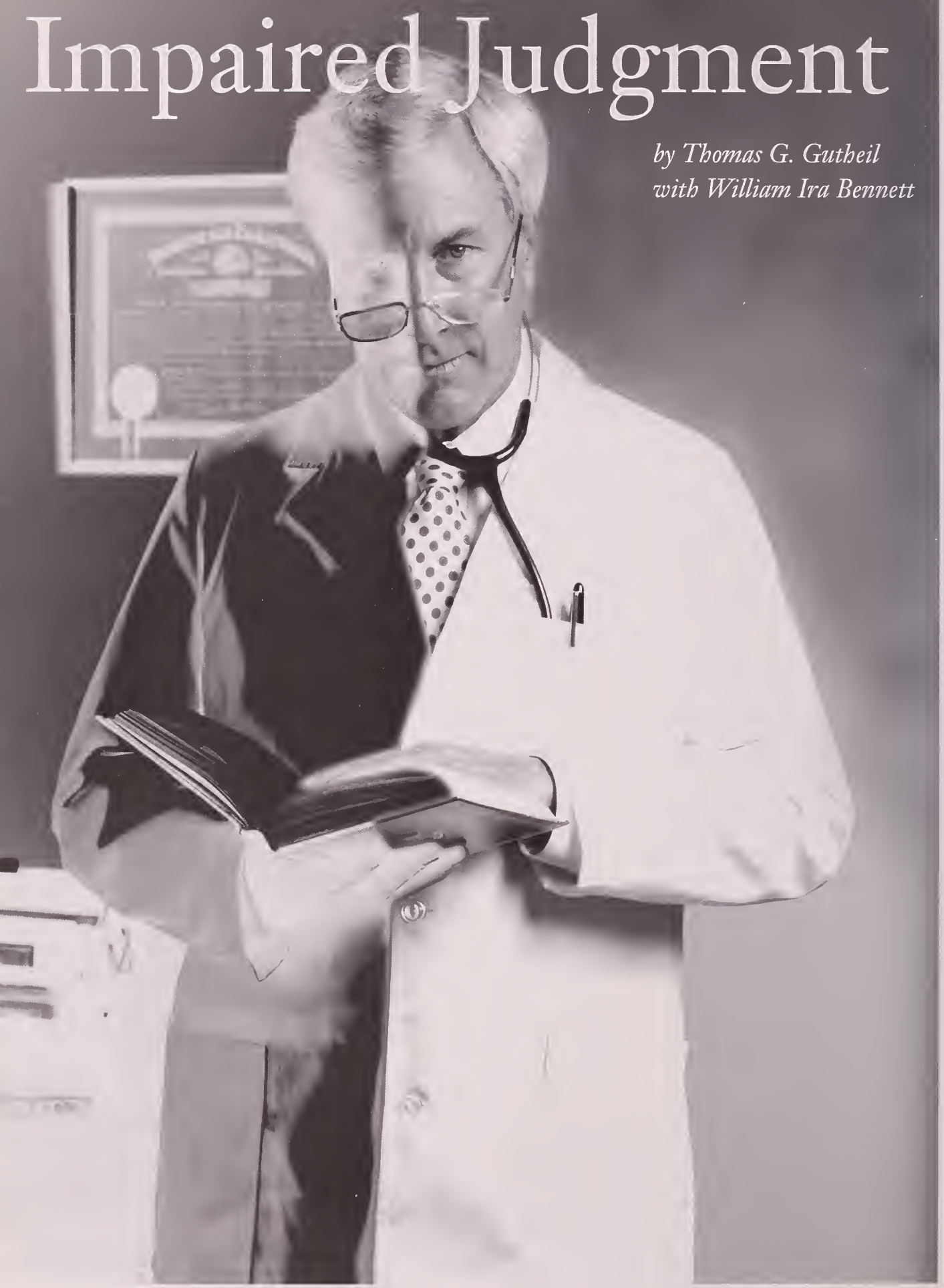
* *To obtain a free copy of any of the three forms of the publication, call 1-800-358-9295: the short* Patient and Family Guide, The Quick Reference Guide for Clinicians, *and the most detailed form*, The Clinical Practice Guideline.

Impaired Judgment

by Thomas G. Gutheil
with William Ira Bennett



On July 26, 1990, the Americans with Disabilities Act (ADA) was signed into law. Thirty-seven days later the National Practitioner Data Bank began collecting and disseminating information on physicians' malpractice payments, burdens on their licensure, and instances in which their clinical privileges had been lost or restricted.

The ADA extended federal protection to "qualified" people with "impairments" that "substantially limit one or more . . . major life activities." The data bank could be viewed as a crude effort to identify certain kinds of impaired physicians and "flag" them out of practice.These two federal entities are meant to serve as channel buoys marking the Scylla of intolerance and the Charybdis of practitioner incompetence.There are, however, important ways in which they have served to muddy the waters for physicians, their employers and their patients.

Many physicians have significant disabilities and yet are able to practice medicine in their chosen field at an extraordinarily high level. Not only that, both the person with the disability and his or her peers can agree whether the disability interferes with quality of care. But in one area this may not be possible. If the disability is psychiatric—either a mental illness or a problem with substance abuse—the difficulty of finding common ground can in some cases be overwhelming.

John W. Campbell, who edited the science fiction magazine *Astounding* (later *Analog*), once wrote a parable about judgment. An airline pilot is in a cabin that is very slowly losing pressure. At some point, the pilot is going to lose his ability to make good decisions about how to fly. When will he know that has happened? This second-order awareness, judgment about one's own judgment, is one of the most difficult tasks of self-observation, far harder than assessing external phenomena. Perhaps a close second is the ability to assess whether another person's judgment is intact when it has been more-or-less subtly challenged, whether by slight lack of oxygen, mild intoxication or the subtle effects of mental illness. And an even closer third is the sheer willingness to confront a person whose judgment appears to be impaired.

For good reason airline pilots and physicians are often compared, as lives depend on their ability to perform at peak levels of competence. Airline pilots are, however, in some ways more closely scrutinized than doctors. They are compelled to report more about their own health and their use of prescription medication, and they must periodically undergo physical examinations to meet the standards of the Federal Aviation Administration. Even though licensing and credentialing procedures may seem like onerous tasks to physicians, relatively speaking, doctors are allowed much more scope for self-monitoring than pilots are.

For a physician with a psychiatric illness, self-monitoring is one of the most problematic of tasks. The surgeon with Parkinson's disease has a brain disorder, but by nature of the illness can make the intact observation that his or her hands are tremulous. But when a physician is bipolar, has obsessive-compulsive disorder, begins to experience paranoid thoughts, or believes that "just one" drink or snort won't matter, the entity contemplating the problem is also the site of the problem.

The risk that a doctor will misjudge his or her own competence and go unchecked is perhaps greatest in that vanishing ecosystem, the solo private practice, but there is abundant evidence that even very good institutions often lack the capacity to pick up on florid wrongful conduct, let alone clear evidence of judgment impaired by alcohol, drugs or mental illness.

A particularly vivid example is given in the *New Yorker* of November 24, 1997, which carries an account by James B. Stewart of the professional and criminal career of Michael Swango, MD. Swango appears to have an archetypal antisocial personality disorder and a compulsion to kill, often by poisoning. According to Stewart, Swango graduated from Southern Illinois University School of Medicine, even though a question had been raised about his honesty during his clinical rotations and he had been asked to spend an additional nine months in training. He subsequently managed to obtain training positions at Ohio State University, the University of South Dakota, and the State University of New York at Stony Brook, despite a prior conviction in Illinois for poisoning fellow EMTs and, after Ohio State, indications that he had poisoned patients.

Under suspicion of causing several deaths in New York, Swango eluded arrest, left the United States, and went on to work in several African countries, among them Zimbabwe, where he is suspected of poisoning seven people and causing five deaths at Mberengwa Hospital during the month of July 1995. A placement firm with branches in Boston and South Africa arranged for him to take a post in Saudi Arabia in June 1997, but to do so he had to return to the United States to obtain his visa. Almost by accident, he was arrested in Chicago and turned over to federal authorities. At the time of the *New Yorker* article, he was in custody in New York but not yet charged with murder.

What I want to emphasize is that the institutions involved had great difficulty screening out this apparently very persuasive and charming man, and that as he went from one system to another, the administrators and faculty involved were unable to transmit to each other or to the appropriate authorities their real experience of him and, in some cases, their suspicions that he was terribly dangerous. Yet, as I read the article I found nothing in it implausible. I never asked myself, "What the hell are these guys doing?" because I knew exactly what they were doing and why they were doing it.

Criminal activity, even if it represents psychopathology, will obviously never fall under the purview of the Americans with Disabilities Act (ADA). Swango's story is nevertheless instructive. Here is a man with a severe character defect (which might be construed as a mental impairment) that became progressively more manifest. In the service of fairness, however, his reputation was protected despite increasing alarm about his activities. The standard screening practices of several reputable institutions were ineffective in preventing him from practicing his brand of medicine. The National Practitioner Data Bank, which is intended to mark bad or dangerous doctors, appears not to have picked up any stigmatizing information about Swango (although it only began operations in 1990, five years after his felony conviction). But Swango, despite changing his name, never completely concealed his past or his birth name when submitting applications for medical positions. It is highly unlikely that the data bank would have contained any information he had not himself already revealed.

If the National Practitioner Data Bank had been up and running ten years earlier, would it have been an effective screening device to catch a potentially dangerous physician? Will it be in the future? There is reason to doubt that it will be capable of capturing the critical data needed to identify problem practitioners, and there are at least two reasons for that. First, like most efforts to screen physicians, it is looking for the wrong kind of data. And, second, it depends on reports from local institutions: hospitals and other clinical settings and boards of registration, where there are many impediments to gathering and transmitting relevant information.

Physicians are universally screened for competence, usually quite narrowly defined, and not for character. We put one sieve after another in place, from college grade-point averages to board-certification examinations, and now the data bank, with the fantasy that piling test upon test will protect our patients from danger and us from liability. As fine as any of these screens may get, they rarely have more than the most limited ability to assess critical areas of judgment and ethical sensibility; yet the latter are at least as vital to safe medical practice and reduced liability as the skills more routinely tested. Indeed, this emphasis on a jejune definition of competence probably favors the entrance of physicians with a certain kind of narcissistic character style.

The use of such tests is partly a way of trying to insulate the process of assessment against the vagaries of evaluation within the medical community. It is well established that physicians have great difficulty confronting a colleague about a behavioral problem or taking collective action to contain and manage it, whether the intervention called for is gentle questioning about depression or taking swift action to stop drug-induced malpractice. And even when there is a confrontation, it is likely to be most resisted where it is most needed.

Precisely because we do not screen for character, many physicians respond narcissistically to confrontation: by interpreting it as professional jealousy or sabotage, anything but helpful advice. And these reactions are bolstered by the cultural expectations that physicians will enjoy a formidable amount of autonomy. It is what we are expected and socialized to exercise; it is what we are most comfortable with and suited to. So the notion of consultation, supervision, and other kinds of collegial mechanisms for quality control are often strongly resisted. The situation has to get pretty bad before anyone does anything useful.

The difficulty with putting something like the data bank in place to cure the problem is that it may actually be counterproductive. First, it chiefly reports malpractice payments, a highly misleading measure of risk if taken at face value. For example, the information that a patient died and the physician settled a malpractice claim for only $30,000 is strong evidence that there was no liability; the case was settled to make it go away. How many users of the data bank realize this? Even quite rational and well-informed people may not know the calculus used in malpractice decisions.

Second, the data bank records disciplinary actions taken by medical boards, hospitals and clinics—and we're right back where we started, with professional groups that resist finding clinical fault with a colleague. But now, with the knowledge that such actions have to be reported to the data bank, there may be greater resistance to taking action, and it becomes almost strategically required for the doctor in question to challenge all such actions, lest they go into the data bank and he or she has to provide an explanation to every subsequent employer.

All that said, I think we are at a point where we can identify the wrong approaches to quality control: more punitive accountability, more and finer sieves providing narcissistic rewards (certificates) for a certain kind of competence. These are, however, the main approaches in current use.

And this fact makes it very difficult to approach the problem of both supporting and monitoring physicians with psychiatric disabilities. Consider, as just one example, the physician with bipolar disorder. The natural history of the illness is such that many people with it can enter medicine; indeed a tendency to hypomanic productivity may actually be favored. Effective treatment can eliminate the symptoms, but the illness is often either inadequately treated or treatment-resistant, and then there is a relatively significant risk that the patient/physician will get into a state of manic entitlement, disinhibition, and hypersexuality leading to financial irregularities, research irregularities or sexual misconduct. (Occasionally, depression in the clinician may also warp judgment by creating the sense that intimacy with a

patient can restore well-being. Depression may also play out more subtly by affecting the physician's management of end-of-life needs.)

In the spirit of the ADA, is a mood disorder a protected disability requiring accommodation, and if so when does it disqualify a physician from practice? What about a physician who meets the criteria for borderline personality disorder? Such a physician, in the nature of the disorder, would often function at very high levels, but predictably would also have difficulty getting along with colleagues, would enter into complicated relationships, would become overinvolved with patients. In this case, is a DSM-IV diagnosis also an ADA disability? How would you design a program to accommodate this physician?

Without too much imagination a program can be developed for someone who is wheelchair bound. What would a program for a physician with borderline personality disorder look like? The ADA provides a tidy, if theoretical, way to resolve some of these questions, although it doesn't specify which psychiatric conditions come under its purview. The act protects disability as such and places the onus of quality control on job descriptions and supervisors: measure job performance, and make suitable accommodations for the illness.

But how much risk should a medical institution absorb in honoring its ADA mandate? How does it balance the ADA with its implicit, and now often explicit, mandate to carry on the self-policing activities required for patient protection? These aren't answered questions.

The purpose of the National Practitioner Data Bank is, fundamentally, to stigmatize certain practitioners. The purpose of the ADA is to protect people in various social roles, including that of employee, from stigmatization on account of disability. We have, in a way, reached a point of minimum clarity.

What is the route out of this dilemma? Unfortunately, it is not obvious. Adding legislation or attempting to fine tune what we have seems unlikely to solve the problem. The task is to develop institutions that are both more responsive to these issues and braver in addressing them than is currently the norm. I think the task is to create an appropriate moral atmosphere, one that is both clear about the mission and open to conversation about these issues. In the nature of institutions, the initiative to do this must come from the top, where someone has to be willing to sit down and hash out these morally ambiguous and personally tragic issues. But people who like to be at the top do not typically have a predilection for openness.

It is not the right solution when we ask a problem physician, "disabled" or not, to leave our program and hope he or she will go elsewhere, even though this tack may be the least burdensome for administrators threatened from several directions with litigation motivated by the ADA or the data bank. Finding a balance that is fair to the physician while reducing risk to an acceptable level is extraordinarily difficult in an environment where confusion and unrealistic expectations about risk abound.

The difficulty will certainly be intensified by the progressive consolidation of medical institutions. As they get larger and more centralized, and as efforts to cut costs proceed apace, the expensive (in our case, the cost of making accommodations for the disabled) physician is likely to have a much harder time, and institutional solutions are more likely to reflect bureaucratic imperatives than a community response.

Which brings us back to the matter of character and our failure to assess it carefully. Character is the best predictor of good judgment, including judgment about one's own judgment. The physician whose self-esteem is not rigidly dependent on looking good and who is capable of responding openly to feedback, no matter what his or her "disability," is likely to be the safest physician.

It's arguably the best strategy for a physician with a psychiatric disability to recruit colleagues as monitors because they can be very helpful. If they don't know what's going on and haven't been apprised, the initial reaction to emerging symptoms is likely to be either avoidance or overreaction. But without collegial openness, this approach is unlikely to be experienced as safe. Our need is for leadership to establish an institutional atmosphere in which a practitioner's disabilities can be honestly assessed and safely managed. If we can't be open about this sort of thing, who in Western civilization do we think can be? ❦

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Skeletons in His Closet

by Alfred Worcester

This chapter is from the unpublished reminiscences of Alfred Worcester, which have been edited by Worcester's great-nephew Richard B. Beaman, the A.W. Mellon Professor, Emeritus at Carnegie-Mellon University.

Late in September of 1881 I began my medical school education. The regular course of instruction was then for three years with an optional fourth in the specialties of medical practice. One could escape attendance for the first year by registering with an outside doctor as his pupil before attempting the examinations. This I had done. Altogether I had only eleven months of formal education in the Harvard Medical School before achieving my MD degree in 1883. Early in my practice I regretted that little medical education only to later enjoy teasing my better educated colleagues with the claim that I had less of the obsolete to forget.

The medical school was then housed in an old brick building on North Grove Street, infamous locale where Professor Webster murdered Dr. Parkman nearly 40 years earlier, right next to the Boston City Stables—about equidistant from the Massachusetts General Hospital and the Charles Street Jail. It was a glum, poorly lighted, badly ventilated, overcrowded building with an adjoining wooden shed with skylights. Through large barn doors of this shed a mysterious covered wagon would occasionally arrive, bringing corpses for the dissecting room in the western part of the shed. Its arrival occasioned excitement among the students, for corpses or "stiffs" as we called them were so scarce that students were always behind their schedules for dissecting.

Since by day the tables were in full use by first year students, we had to do our work by feeble gas lights at night. As that was before corpses were embalmed, the stench was terrible. Body snatchers were not always successful in getting recently buried cadavers. Since a great public outcry against use of bodies from state pauper institutions cut off that source of supply from medical schools, we had to make do with whatever we could get, and when.

H.H.A. Beach was the Demonstrator of Anatomy. I learned little from him but he kindly let my slovenly work pass by mid-years, very fortunately for me, too, because I then became desperately ill. Whether it was from dissecting room poisoning or from septic surgery, I never found out. What I recall is that on Ash Wednesday, too miserable for work, I went to Trinity Church for the afternoon service. Leaning back against the fluted column opposite the pulpit in my usual place, I did not hear Phillips Brooks begin before I realized he had finished. Then I knew I was ill. For several days I had a painful swelling under my jaw. Seeking relief, I went not home but to the house of the MGH internes, some of whom I knew very well. They told me I had a high fever, that the abscess under my jaw must be immediately opened and poulticed, and that I must go to bed

Then one of them, dear Ally Wakefield, whipped out from his pocket surgical case a knife (which had never been sterilized since it left its maker's forge) and lanced my abscess. A poultice was soon brought and with bandaged head I started off for Waltham, obstinately declining their offer of a bed. I repented my refusal every step of a long mile-walk home.

The erysipelas that followed prevented my return to the school until June. With hairless head and full grown beard I met with classmates' questioning, "Worcester, where in hell have you been?" With the help of their notebooks I soon went in for my examinations and passed them.

What I may not have told before was that in delirium I had constantly talked of a crime I had committed which would destroy all my hopes of ever being a physician. Now at last I make a full confession.

After finishing my last dissection I had won possession of the skeleton from my four partners by lot. In those years, long before x-raying, every country doctor was supposed to have a skeleton in his closet by which to remind himself of the bone he might then be called upon to set. Skeletons cost around 30 dollars. For five dollars, however, the janitor would boil the bones so that the student could then easily scrape them clean.

My bargain with the janitor required me to disjoint the bones, bag them and hide them in a cupboard in Professor Bowditch's physiology laboratory. This must be done at night. I

had just done so before my illness although I am not sure I had alerted the janitor. At any rate, in my delirium I believed that Dr. Bowditch had discovered these bones as the cause of the stench and had threatened the guilty student with expulsion. Four months later I read on the bulletin board his request for any information that would lead to the detection of the culprit. I did not confess, much to the janitor's relief. Nor to my lasting regret did I ever have any acquaintance with Dean Bowditch, even though one of his daughters became my patient. It is not a pleasant story, yet one which does set forth the sordid conditions of medical education in the early 1880s.

The most famous member of the faculty was the professor of anatomy, Oliver Wendell Holmes. His lectures furnished such entertainment that many attended who were not then enrolled in his class. However dry the bones were that he was describing, they came to life under the illumination of his brilliant imagination. For example, when describing the pubic arch, holding up one of the bones he told us, "Under this noble arch every human being, on entrance into this world, reverently bows its head upon its breast."

I had missed the Oliver Wendell Holmes inimitable lectures in anatomy. I did get their flavor when rumor circulated that a special topic would be discussed by the autocrat, as some nicknamed him. The old amphitheater would then be packed by students of all classes, even by old graduates, an audience never disappointed. His wit was not really as spontaneous as he wanted it to appear, yet so polished that there was usually a double pun or witticism to look for while laughing at the first. For example, when speaking of the rounded cushion stump of the soldier's amputated thigh he said, "How can the surgeon fail to acknowledge there's a divinity that shapes our ends," and then, bowing to the surgeons in the front seats, "rough hew them as we may?"

Alfred Worcester

In great contrast to Holmes in personality, although equally thorough masters of their subjects, surgery and chemistry, were professors David W. Cheever and Edward S. Wood. Their lectures were superb. Neither of them used a superfluous word or even smiled. They fully appreciated the life-and-death importance of their teachings. I have always wished that I had not lost so large a part of it, for what I did have stood me in such good stead. Had I not learned from Professor Wood the importance and processes of urinalysis, I should not have saved a patient who was near her death from arsenic poisoning. The source of this was finally traced by my brother-in-law, Professor W.B. Hill, to the buried wallpaper of her chamber. He discovered that when a wallpaper containing arsenic is covered with a paste for a new paper, the deadly gas of arsenic hydride is set free. This particular case was one that brought about government regulations elminating the use of arsenic in wallpaper.

While many of Professor Cheever's surgical maxims hold good today, one of his sayings sticks in my memory as evidence of the revolution that has taken place in medical science since my student years. In his discussion of the nature and treatment of malignant pustule he told us, "A Frenchman (Pasteur) claimed that a certain germ or bacillus was the cause of the disease," adding, "those who so wish may believe it. I do not." That was the only mention of the germ origin of disease that I heard during my medical school student years, 1882 and 1883.

From the professor of obstetrics, John P. Reynolds, a lovable man but a poor lecturer, I learned much worth remembering. Fond of metaphor he sometimes mixed them so badly I could not always be sure what he was talking about. Dr. Reynolds, a man of noble bearing, grace and old-fashioned courtesy, was certainly religious. A story about him is characteristic. Once while attending a woman in her perfectly normal labor, her husband, finding him on his knees in a nearby room, tremulously asked if his wife really was in such grave danger. The dear old doctor replied, "Oh no, she is doing very well, but in helping a woman in the perils of childbirth I always pray for our Creator's grace that I may worthily cooperate with Him." Such religious faith seldom found expression in Harvard circles in those times.

In no other branch of medical education has there been a greater advance in this century than in obstetrics. Largely, this has been due to the discovery of the germ origin of childbed fever which in my student years was the cause of fearful maternal mortality. Even more horrible in my memory of those years was the teaching and practice of child destruction in order to save the life of the mother when delivery through natural channels was impossible. I know of no more devilish instruments than those devised for this purpose. And yet, halfway back to my student years, in reporting a case

where I had to send back to my office for these instruments I was mercilessly criticized for undertaking such consulting obstetrics service without carrying with me these instruments for child destruction. Only after the certain death of the unborn will such dismemberment be the best procedure. Happily, since Cesarean operations have become so common there is no longer need to fear that exigency.

Another great improvement in teaching was just beginning at HMS in the years I am describing. Students were being sent to serve as doctors in the homes of the poor. If any student found himself in difficulty, he could send for help from the senior interne at the Lying-In Hospital. To William L. Richardson, a top-notch instructor in operative obstetrics, I believe, is due credit for this advance both in medical education and in social service.

I suppose every physician more vividly recalls his first obstetric case than any other of his hundreds of subsequent cases. However that may be, I shall now describe my first case not for its intrinsic importance but as an illustration of medical education amidst the social degradation of the early 1880s.

In bitterly cold weather I was sent to take care of a young woman in labor whose pains had failed to bring forth her unwanted child. She was a poor ragpicker, befriended in her misery by a pair of fellow workers, perhaps a married couple, whose home consisted of only one room in an old house located in what once was Boston's fashionable North End. The man had moved downstairs into the coal hole to give his place in bed to this poor, ill-shapen girl who had been turned out of her former lodgings because of her illegitimate pregnancy. Not for two days did I recognize the utter hopelessness of her unproductive labor. During this time, while I was following too strictly my instructions to not send for help needlessly, I left the stuffy room only for brief snatches of restaurant food and even more needed fresh air.

At last I sent for help, telling my story to Ben Simonds, my classmate who had become senior interne at the Lying-In Hospital. With forceps he at once delivered the girl of a wizened child who was never able to suckle her mother's breasts. After a few days of feeding spoonful of whatever kindly callers suggested, it became evident to all that the child could not live much longer. The mother and her friends were more than willing for me to take it to an infants' hospital which my cousin, Dr. Thomas M. Roach with Dr. Haven had started on Blossom Street. I had obtained permission from the kind matron, Miss Bush, but when I brought her the dying baby wrapped in rags, Miss Bush had some hesitation about admission. To save the baby from freezing I had kept it near my own body under my overcoat. I have never believed that the baby's death was from smothering nor did the autopsy so reveal. I do not know how many city and state laws I broke in this instance or afterwards in some other cases where illegitimate babies and their distressed mothers were concerned.

Of many other professors, instructors and lecturers of that time I have only vague memories, except that I passed their examinations by help from borrowed notebooks. No student, however, who ever took the quizzes of Professor R.H. Fitz can have forgotten his insistence upon exact words for the description of pathological specimens. He was a great teacher of accurate observations and of logical deductions therefrom. As only the word Waterloo is under the picture of the Duke of Wellington in London's National Gallery, so of any pen-portrait of Fitz, the only word needed is Appendicitis.

Among those nearly forgotten was the Professor of Materia Medica, whose lectures were as dry as the herbs he described. However, this reminds me of a visit he had some of us make to an old drug establishment in Boston where bunches of dried herbs, waiting to be made into powders, pills and mother tincture, reminded me of my great grandmother's attic where hung bunches of hardhack, spearmint, boneset, thorough root, hoarhound and I know not how many others from which she made infusions or teas, as such nauseous but supposedly healing drinks were called.

H. J. Bigelow

I have always believed that in the old curative herbs and animal products there was more virtue than has been recognized in these later years. Yet, what could modern doctors do without morphine, atropine, quinine, the digitalis derivatives, insulin and the liver extracts? In my student years the medical trend was towards derivatives from coal tar, anti-febrin as acetanilid then was called, the first of a long line of the chemical products that displaced medicines made in nature's laboratory. Now comes the return to it, to the lowly molds, to penicillin and its partner, streptomycin. Great has been the revolution in materia medica.

The most distinguished member of the faculty was Henry J. Bigelow who became emeritus while I was a student. His fame was international. In both London and Paris he had demonstrated at least two of his remarkable surgical advances. One was the way to reduce hip dislocation easily and without further injury to the ligaments. Before this discovery the only way was by hauling the leg so forcibly as to tear the ligaments of the joint. This force was furnished by use of a block and pulleys to greatly increase the surgeon's pull. Bigelow, after long study of the hip joint discovered the Y ligament and thence how to move the leg so the ball of the femur would slip back into its socket. This he could do with only one hand. What is of more importance, he could teach this procedure even in printed words. One of his exploits became a famous story of the time, that he saw a woman fall on the icy pavement at a Boston street corner, went to her relief, made the correct diagnosis, reduced her dislocation and raised her up on her feet.

The other advance in surgery likewise developed out of long study and experimentation. Curiously the disease of bladder stones, once so common, has almost disappeared. This somewhat diminishes Bigelow's fame for inventing instruments for crushing and removing such stones from the bladder. But to him goes the credit for making possible, by way of the urethra, all kinds of surgery formally necessitating body incisions. I count it a great privilege to have seen Dr. Bigelow operate in the Massachusetts General Hospital; but I am glad I never had interne service under him, for he was a temperamental task master, though he was regal in his carriage, self-willed and very receptive to his colleagues' homage.

Another great teacher, Calvin Ellis, resigned from his professorship in my student years. He was also dean. Unlike Henry J. Bigelow's dazzling personality and career, Dr. Ellis' quiet modesty never attracted the fame due for his advances in the science of medical practice. To his acumen the whole medical profession is in lasting debt. He taught us a way to discover from what a patient suffered by differential diagnosis. Before his teaching of this method doctors made their diagnosis by comparing the patient's symptoms with those seen in other cases or perhaps only read about in books and journals. That was guesswork, which might or might not give the right diagnosis upon which the proper treatment depends. By the differential diagnosis method the doctor, after assembling facts obtained in the examination of the patient, must also mentally assemble the characteristics of all the diseases from which his patient could be suffering. Then he must eliminate one after another until he finds one that cannot be eliminated. Nowadays we take this method for granted.

I never heard Dr. Ellis lecture but I came under his teaching in conferences where students in turn had to give their reports on assigned cases. Mine was a case of pneumonia. After reporting the course of the patient's disease, I offered the suggestion that since pneumonia and erysipelas are so alike they must have the same cause. The sudden onset of a severe chill, the same temperature charts, and above all, the location of the inflammations in the same embryologic middle layer of the body make it at least highly probable that both diseases are caused by infective germs which have penetrated in pneumonia the inner embryological layer (the bronchial mucous membrane) and in erysipelas the outer layer (the epidermis).

This theory somewhat amplified was the basis of my thesis for winning my MD diploma. That would have been the end of it had I not previously read it at a meeting of the Boylston Medical Society to which I had the good fortune to be elected. There my thesis attracted some attention. In later years I was pleased when one of my classmates, Henry Jackson, held that mine was the first reference in Boston to the germ origin of pneumonia. However that may be, I can claim priority as the earliest HMS student to have taken both bacteriology and embryology in pursuit of my AM degree, both subjects now considered necessary foundations of medical education.

In my sketches of professors whom I especially recall I am not attempting to give any account of the whole faculty. Some of them I barely knew by sight, those whose course schedules conflicted with my own four lectures a week that I was giving in a Boston private school, or whose teaching was in the months of my illness.

Then as now I was more interested in the art than the science of medical practice. Such lessons, I soon found, could only be learned in the clinics. There were fine opportunities in those years. I was fortunate to be assigned to the clinic conducted by Fred Shattuck in the St. Elizabeth Hospital, then full of consumptives. He taught me how to percuss and auscultate the chests of poor, dying girls, better yet, how to soak my hands in hot water before touching them. Fred Shattuck was nowise behind in the science of medicine for having been foremost in the art of its practice. In his fortieth year he almost despaired of being able to earn his living as a doctor, gave himself one more trial year before giving up in

Babies at the Boston Lying-In Hospital, 1899

favor of some job in business. Fortunately, during that year, his practice grew by leaps and bounds.

Among the many other instructors in the clinics of the out-patient service was John Elliot, one of the best teachers and that too in the most unpopular branch of medical practice, gynecology, which was then slowly emerging from darkness. My readers will hardly believe this part of my story. Only those of my own great old age can remember how common it was once for fine healthy women to become hopeless invalids after childbearing, and yet how often such women after dark or alone in the wards would seem to be in the best of health. Many of them were supposed to be bedridden or so mentally afflicted that they were to be seen only by their family members, or perhaps by intimate friends who knew the mysterious nature of their infirmities.

Nine times out of ten such women had suffered injuries in child-bearing which deprived them of all control of excretions. The so-called fine ladies were not the only ones too sensitive to apply for medical help. In fact, if they did apply, the doctors could give no help until a young Alabama surgeon, Marion Simms, taught them. He began his study of the problem with Negresses no longer of any use to their slave owners. After finding out how to repair such injuries he became world famous. One of his patients was Eugenie, Empress of France. He taught doctors his methods.

Hospitals for women began to spring up. But so great was the opposition to male surgeons' service of this character that female doctors were needed. To the general surprise, it was soon found that female doctors especially disliked such service, and began to clamor for recognition as general practitioners and for admission to all medical schools and societies. Such was the situation in my student days. Only now in 1945 has HMS decided to admit women students.

During these three-score past years there has been a marvelous change in medical care for women. Such injuries as so many suffered in child-bearing are now either prevented or immediately corrected. Women without the false modesty of the past now naturally expect their doctors to care for their whole body. The specialty of gynecology, which began in the 1850s and was a troublesome Boston infant in the 1880s, has been steadily accepted.

So long an account of a medical specialty may seem to be a diversion from my subject, yet it is a necessary ingredient for any description of HMS in the 1880s.

John Homans, Uncle John as he was affectionately called, was a specialist of the specialists, famous only as an ovananatomist, his Harvard title. He was a great favorite and had a lovely tenor voice. In selected groups students were allowed to witness his operations in the refined little hospital of the St. Margaret's Sisters in Louisburg Square. Ovarian tumors, before his time, incapacitated many women; some were bedridden. The tumors were bags of fluid not seldom weighing more than the rest of the patient's body.

Uncle John's solution was of ideal simplicity. By a small incision through the abdominal walls the bulging bag could be pierced by a pointed tube, a trocar. After the tumor was thus drained, the shriveled bag would be tied, cut off and the stump dropped back into the abdomen, or more often stitched to its wall. Under the meticulous cleanliness of the sisters' care, subjects of such surgery almost always recovered perfect health. Amateur surgery as it was, we students had awesome respect for Uncle John's bold mastery of an hitherto incurable disease.

William H. Baker, the professor of

Harvard Medical School, North Grove Street

gynecology, was an altogether different type of man. Smooth and sweet, not bluff and hearty, with his gilded instruments in profusion he magnified the importance of Marion Simms' reparative operations and the cost of them, at private hospitals. His extortions and worse, his continuous visits in the treatment of rich patients by internal massage for imaginary complaints, won for him besides their gold, the righteous contempt of his colleagues.

As an example of this hostility I was begged by the then president of the Massachusetts Medical Society to avoid in general practice all taint of gynecology. When he stated that never had he uncovered a patient and I had asked him how then he could be sure after child-bearing that she had not been injured thereby, he proudly averred that never had such accidents happened in his practice of delivering women under their bed clothes. Years afterwards when one of his former patients came under my care I found that she had been terribly torn. As another example of the hostility of the medical profession in those days, I was warned by a distinguished professor of the Dartmouth Medical School to avoid all connection with the "dirty gynecologists."

In returning now to John Elliot's teaching in my student days I can offer real refreshment to my readers. My first glimpse of Dr. Elliot was when, tagging along in Dr. Bigelow's wake in the ward of the MGH, I heard him say, "She has some pelvic trouble. Send for Jack Elliot. He will examine her internals as I never do." He did soon come, made the examination and reported his findings. I was deeply impressed by his directness, his skill and knowledge.

Soon I found myself at his outpatient clinic at the City Hospital, where he taught small groups of students to make the diagnosis of pelvic diseases. They were taught by the German method, not by telling them what they would find but by questioning them on what they found. His was the best kind of teaching, like that of Professor Fitz.

More than that, his courtesy and kindness to those women was a valuable lesson which came not from German clinics but from his own chivalry. He was not merely an expert gynecologist for that was only a branch of his excellent general surgery. It was he who saved my life by boldly operating on me when others contended I was too far gone with appendicitis. It was Elliot who a few years later was my only backer among Boston surgeons when I fought for immediate surgery in cases of appendicitis.

Besides the clinics of the professors and instructors of the school we had the advantage of witnessing operations in the amphitheaters of the hospitals, also of walking through the wards with doctors not necessarily connected with the school. Especially from one of these, George G. Tarbell, I learned many valuable lessons. He taught us to allow typhoid fever patients semi-solid food against the dictum then current of giving only fluids. I was reminded of

this in Germany when I saw plates of thick roast ham and heaps of spinach given to such patients by Bismark's favorite physician, one said to be the only man Bismark dared not disobey.

Dr. Tarbell told me, "You Americans give only fluids to your enteritis patients, and it takes them months to regain their strength. My patients walk home after the fever is over." As soon as I began my practice Dr. Tarbell turned over to me his Lincoln (Massachusetts) patients, including his own mother. In those early years he was often a great help as my consultant.

Typhoid fever, common then, has so far disappeared that young graduates in medicine sometimes ask us old doctors if we have seen cases of it. So typhus, smallpox and diphtheria have become rare. I believe tuberculosis will follow them into oblivion. Already homes for the shelter of dying consumptives have given place to sanitariums for the care of those with tuberculosis. It is therefore impossible to give to those acquainted with modern hospitals any vivid picture of what were rightly called the foul wards, which we remember where patients were dying every day of diseases now almost extinct. Not only the patients, the nurses and young doctors often died there of the diseases they were fighting.

Now it was time for me to start my interneship at the Boston Lying-In Hospital before quite finishing at HMS. For lectures missed I was saved once more by my classmates' notes. I was so poorly prepared for my final examinations that I hardly expected to pass. To my surprise, I did. As an illustration of the value of such examinations as a test of knowledge or ability, my mark in surgery, of which I knew nothing, topped Pfeiffer's by as much as his mark in obstetrics topped mine. He had won a surgical interneship at HMS, had been doing fine work there while I had been at the Lying-In.

I had expected to take the elective fourth-year course, supposed that I was so registered when to my surprise some classmates reported that my name was posted among those to receive the medical degree the following day. This had to be a mistake because I had not yet taken some required courses. No matter, I went out to commencement just on the chance and was handed my degree by the president. I dare not say that my degree was given to me after only 11 months' work in the medical school, yet such was the fact.

Alfred Worcester, Class of 1883, was an expert in obstetrics and a highly respected family doctor in Waltham, Massachusetts, who at age 70 was named the HMS Henry Kemble Oliver Professor of Hygiene. He was an advocate of early surgical treatment of appendicitis, did the first successful Caesarian section in Massachusetts, founded a training school for nurses and the Waltham Baby Hospital, and served as president of the Massachusetts Medical Society in 1919. He lived from 1855 to 1951.

MGH operating theatre, 1889, with John Warren among those present.

Minding the Store

by Joseph Lacherlich

I JUST OPENED MY PRACTICE IN THE most expensive hardware store in the world. I have a little cubicle in the vast football field they call Ace Medical Hardware. It has two personal bathrooms, which demonstrates my importance.

On the first day, I spent an hour with an energetic woman who had been brought by the police for threatening to blow up her boyfriend with a bomb. She was a charming and nonstop lecturer, who explained with a smile that she was merely practicing self-assertion. The boyfriend had taken it wrong. I admired her logic, and hoped the police could see things her way.

The police then brought me another lecturer, who had had a stroke a few years ago. They had picked him up, walking down the road to Chicago to save souls. I spent an hour with him as well, changing the subject when he got to touchy topics. He got awfully excited about shaking a crying child to make it stop, and I didn't want him to try it on me.

These two conversations put me in the hole with the administrators, who then brought 18 patients to me in the next hour and a half, or one every five minutes. I wrote fast: "diagnosis, depression; treatment, Paxil, 10 mg., etc." In fact, I spent almost all of the hour and a half writing, looking up occasionally to make sure the patient was in the room. Even this was not reassuring, for I could not help thinking of a saying of one of my teachers: "The brain is in the cranium, but the mind may not be in the room."

I felt strangely tense after this athletic feat and went to lunch to gather myself again. Returning overconfident, I spent yet another hour with the mother of a boy who had just had a psychotic break and the wan boy himself. She had a little notebook of her concerns, and I heard them all out. Item: "Henry went for a ride yesterday with his sister and her fiancé and didn't say anything." Henry mumbled, in his own defense, but he could no more justify himself than could Walter Mitty explain to his wife why he didn't have galoshes.

By the end of this hour I was ready to punch somebody. I ran out the day somehow, and went to my mailbox. The administrators must have been watching my day, for their memo addressed the very trouble I had been in. From this day forward they ordered that all medical personnel would get a daily schedule of when patients would arrive. We were to meet every single one of them, on time, like trains.

The new day dawned, and I went to my cubicle in the vast medical plain. The first two patients, 0800 and 0815 did not show up, so I began to wander around the hardware to amuse myself. This was a mistake, because a black woman entered my office at 0830, and I did not discover it until 1000. I discovered it only because a fat white woman passed me in the hall, going as fast as the white rabbit himself.

So I followed fast down the hall, and ran into another woman coming out of my cubicle very upset. I sat down with her right in the middle of the hardware on the floor. She needed to build something out of wood, so I sawed a hole in the wood floor about 12 square feet, and we sat down in this generous space one floor below the main floor of the hardware. One of the officious little men with the blue